University of Alberta

The Experience of a Sample of Canadian Men with Breast Cancer

by

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Abstract

Breast cancer is a devastating problem in North America, accounting for 30% of new cancer cases annually. Canadian statistics for 2004 indicate that 21,400 cases will be diagnosed and 5,300 women are expected to die of this disease. Male breast cancer is less common, accounting for less than 1% of all breast cancer cases. While recent reports suggest that male breast cancer rates are increasing, little is known about what a man experiences when diagnosed with breast cancer.

The goal of this study was to explore the experiences of men diagnosed with breast cancer using narrative method. Through their stories, the participants gave voice to their experiences battling an uncommon and sometimes socially difficult disease. General narrative types in the form of restitution, chaos or quest became apparent within each story. From their experiences and suggestions, I have provided recommendations for improvement.

Acknowledgements

No-one can say it better than Arthur Frank: *"the meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking"*.

For though they are adults now, they will always be my little ones. The effort and time necessary for my degree and thesis project inevitably stole precious, irretrievable moments from them. I ask their forgiveness and give credit to the patience of my children, Aaron and Adele. May your journeys in life fulfill all of your wishes.

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If you wait long enough, it's over.

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Chapter 1 – Introduction

Breast cancer is the most frequently diagnosed malignancy in Canadian women and accounts for about 30% of all cancer cases. It is difficult to turn on the television or open any women's magazine without hearing about a woman battling this illness. Statistics Canada 2004 estimates indicate that 21, 400 women will be diagnosed and 5,300 will die of breast cancer. Millions of federal and provincial dollars are spent annually in the effort to discover new treatments or cure.

Significant efforts against breast cancer occur daily in many forms. People routinely participate in fundraising events such as weekend runs, fashion shows, golf tournaments, head shaves, gala dinners and auctions in an effort to raise research monies to fight breast cancer. Activist groups muster support among voters and lobby government for increased health-care funding; support groups convene to help those who are in the midst of their experience with breast cancer.

The experience of having breast cancer is well-documented. A database search (PubMed, April 28, 2006) combining the terms 'breast cancer" (149,360 references) and 'psychosocial' (33,312 references) provide 915 references describing the experience, ways of coping and carrying on with living or dying with breast cancer. However, closer scrutiny reveals breast cancer literature, including that of psychosocial oncology does not truly represent the affected population. The increased acceptance of qualitative research in the medical community combined with the feminist movement has given women the voices (and the publications) to make their experiences known to the world. What is not well known is that men experience breast cancer, too.

The Problem

Male breast cancer is less common, accounting for less than 1% of all breast cancer cases (Hayes, 2002). Recent reports indicate that male breast cancer rates are increasing (Giordano, 2004) yet reasons for this are currently unknown. Theorists suggest that men diagnosed with breast cancer are likely to suffer serious psychologic issues such as compromised masculinity or emotional isolation while battling an uncommon malignancy. However, what a man feels when faced with a cancer diagnosis is essentially unknown. Moynihan's comprehensive review of psychosocial oncology publications between 1984 – 1998 indicates that men are overwhelmingly under-represented in psychosocial studies. To date, there are no published North American studies describing what a man experiences when diagnosed with breast cancer. Therefore, the purpose of this study was to explore a man's experience with breast cancer.

Significance of the study

Sandelowski (1994) states that personal biographies of the illness experience have disappeared and are upstaged by the medical staff's opinion and history of disease. She advises that through narrative research nurses can discover (or re-discover) knowledge, uncover knowledge embedded in practise and recover the art of nursing. Koch (1998) advises that listening to the voices of patients through their stories is a powerful means of creating empathic forms of understanding and revealing ways to improve nursing practise. Telling one's story is an active experience between the teller and the listener. In the act of sharing the illness stories, the teller often learns to think differently about themselves and their place in the world (Frank, 1995).

The Researcher

I was influenced to pursue this topic through my position as clinical research manager for a major provincial breast tumor program. Regardless of the type of study, whether qualitative, exercise or drug treatment intervention, I observed that men were excluded from participation. I found this difficult to understand as what literature I could find suggested that when matched case by case, male and female breast cancer patients had similar outcomes. The lack of men participating in treatment trials means oncologists do not really know which therapies are most effective for men, as treatment recommendations are extrapolated from results of female study participants. The general lack of qualitative research including men as participants means that as practitioners, we have no idea what it means for a man to experience breast cancer.

Organization of Chapters

Chapter 2, Literature Review, summarizes current publications related to men's health, exploring how masculinity influences health choices, how men perceive health problems and what we currently know about men's experiences with cancer. I have also summarized recent data on male breast cancer incidence, prevalence and treatment. Chapter 3, Design and Method, introduces the reader to stories or 'narratives' as a research approach to advance understanding of the illness experience. The rationale for this approach and the research ethics procedure are described here. Chapter 4, Findings, draws the reader into the lives and experiences of four men's stories. In Chapter 5, Analysis, the participant's stories are considered in forms as proposed by Frank (1995). Chapter 6, Interpretive Discussion, reviews the stories in the context of the literature, discussing similarities and differences. The contribution of this study is summarized and

potential research directions are identified. Following the reference list, appendices including the consent form and the remaining sixteen participants' stories are attached. These stories are included as an appendix to further support the analytical and interpretive credibility of this project.

Delimitations and limitations

A major strength of this project is that no similar examination of North American men's experience with breast cancer has been published. While the number of participants is small, this sample is considerable as 20% of those who received invitation letters took part. Although literature indicates men are not interested in talking about illness, the response rate to this study suggests otherwise. The open-ended qualitative approach adopted in this project provides another area of strength. The men described what was significant about their encounter with breast cancer while these areas were explored, allowing for the sharing of experiences and development of new knowledge. An investigator-driven interview form or guide may have missed elements considered key to participants.

A limitation to this study is the single time-point approach utilized. The in-depth interview was completed with the invitation to contact me with any additional thoughts afterwards; none of the participants provided further comment. As the ethics committee approval included the stipulation that I not be involved in the recruitment process, I was therefore unable to identify respondents within reasonable geographic access, making multiple interviews unrealistic for this project. Another limitation is that this group of exclusively white men living in a province with publicly funded health care may not

adequately reflect the views of men in other settings. Therefore, further replication of this work should be done to examine the experiences and needs of men in other settings.

Chapter 2 – Review of Literature

Masculine Gender and Health Statistics

For as long as vital statistics have been recorded, mortality rates for men have been higher than those of women (Verbrugge, 1985). Statistics Canada (2002) data show that compared to women, Canadian men are dying at much higher rates in 14 of the 15 leading causes of death. Men are more likely to die from diabetes, cancer, pneumonia or flu, heart disease, disorders of the kidney, arterial diseases, psychiatric events, lung disease, unintentional injuries, suicide and HIV. Men and boys have higher death rates than women and girls in every age group and for all 10 leading causes of death in the United States. On average, men in the U.S. die more than 6 years earlier than women (Courtenay, McCreary & Merighi, 2002). This is especially noteworthy considering that historically, men have had advantages over women in nearly all social determinants of health (Meryn & Jadad, 2001).

Verbrugge (1985) suggests five categories to potentially explain gender-related differences in health: biological risks of disease specific to each gender, acquired risks of illness and injury, psychosocial aspects of symptoms and care, differences in health reporting behaviour, and prior health care. When gender-specific disorders are excluded from analysis (such as complications of pregnancy or disorders of the genitalia), anatomic differences cannot explain the major discrepancies in serious chronic diseases, injuries and deaths between men and women. Authorities in mens' health promotion advise that mens' limited health-promoting activities and increased risk-taking are the contributors to increased morbidity and mortality (Courtenay, McCreary & Merighi, 2002) and suggest that one-half of the annual male deaths in the U.S. could be prevented

simply through changes in personal health practices. Little is known about why men choose less healthy lifestyles and adopt fewer health beliefs and behaviours (Courtenay, 2000a). Researchers are currently examining what it means to be a man in North America, what behaviours characterize masculinity in North America and how these behaviours contribute to health risks.

Sabo (2000) describes the term *hegemonic masculinity* as the "prevailing, most lauded, idealized and valorized form of masculinity in a historical setting" (p. 135). In the United States, hegemonic masculinity accentuates male dominance over women, physical strength, proneness to violence, emotional inexpressivity and competitiveness. Brannon in Sabo & Gordon (1995) characterizes North American male gender expectations as:

1. No Sissy Stuff: the need to be different from women;
2. The Big Wheel: the need to be superior to others;
3. The Sturdy Oak: the need to be independent and self-reliant;
4. Give 'Em Hell: the need to be more powerful than others, through violence if necessary.

Men and boys socialized in the North American culture adopt beliefs and attitudes that personalize their concept of maleness. These beliefs and attitudes are enacted in behaviours that demonstrate maleness to others. These frequently unhealthy and risky behaviors in turn influence male susceptibility to illness and accident (Sabo, 1995).

Masculine Gender and Risk Taking with Health

There is abundant literature indicating that men engage in risky behaviours far more frequently than women. Men tend to take greater risks while operating a motor vehicle than women. Transport Canada (2001) data on trends in motor vehicle collisions

reveal that on average, three and a half times as many male drivers as female drivers are killed and that male drivers aged 25 – 34 account for a larger proportion of deaths than any other category. Men are more likely to drive aggressively (tailgating, passing other cars unsafely), drive under the influence of alcohol or drugs and drive over the posted speed limit (Courtenay, 1998). Young males, either as drivers or passengers, are significantly less likely than women to wear seatbelts in a motor vehicle. Such behaviours put men at higher risk of morbidity and mortality than their female counterparts.

Men are also more likely than women to be employed in occupations that put them at risk for a variety of hazards (Nicholas, 2000). Asbestos, benzenes and vinyl chloride are only a few of the carcinogenic chemicals men may be exposed to in the oil and gas, construction or agriculture industries. Although men constitute just over half of employed Albertans, men account for two-thirds of lost time claims and nearly all work-related deaths. Examination of 2005 workplace incident fatalities, occupational disease fatalities and work-related motor vehicle fatalities reveal one female death compared to 141 male deaths in Alberta (Alberta Government Human Resources and Employment, 2005).

Men's diets are frequently inferior to women's, with higher levels of caloric intake and fewer fruits, vegetables and fiber (Courtenay, 2000c). Compared to women, men have little knowledge about food preparation and nutritional requirements. Although athletic capability and strength are important male characteristics, few men participate in regular aerobic exercise programs (Sandman, Simantov & An, 2000). Obesity is a major problem in North America with significant health sequelae including type II diabetes, heart disease, hypertension and stroke. A case-control study conducted by Pan et al. (2004) showed that obesity increases the risk of overall cancer among Canadians to 9.7%

among men and 5.9% among women. Men who are obese have a higher risk of experiencing prostate cancer and are more likely to have aggressive disease at diagnosis that is less responsive to therapy (Amling et al., 2004).

Nicholas (2000) advises that increased male cancer rates are directly attributable to increased rates of substance use. Men drink alcohol earlier, more frequently and in larger amounts. Smoking rates have historically been higher amongst men, although current rates are close to equivalent. The Health Canada Canadian Tobacco Use Monitoring Survey (2002) showed men (23%) were more likely to smoke than women (20%). Although highly associated with development of lung cancer, tobacco use increases the risk of development of many other malignancies including cancer of the oral cavity, esophagus, stomach, bladder, pancreas, liver and kidney. Excessive alcohol use, whether independently or in combination with tobacco, contributes to the development of cancers of the head and neck, esophagus and liver.

Nicholas (2000) states that overall, cancer incidence and mortality are higher among men than women. Bray & Atkin (2004) suggest that compared to women, men have better and more easily achievable opportunities for avoiding cancer-related deaths, for men have lower rates of hormonally-influenced cancers than women. Malignancies frequently experienced by men are often avoidable by preventative measures including smoking cessation, moderation of alcohol consumption, obesity avoidance, regular physical exercise, and a diet high in fruit and vegetables. This body of literature suggests that initiatives to assist men in adopting activities and behaviours to improve their health would result in major gains.

Masculine Gender and Health Care

While women are likely to seek medical assistance, men often demonstrate their superiority and strength by denying and disregarding physical symptoms (Courtenay, 2000a). Men are less likely to contact a health care professional than women, regardless of income or ethnicity (Courtenay 2000b). For men with traditional attitudes about masculinity, health promoting beliefs and behaviours are considered 'female' characteristics and therefore undesirable. Sandman, Simantov & An (2000) asked men what they would do if they were in pain or feeling ill: twenty-four percent stated they would wait as long as possible before seeking help, 17% stated they would wait for at least a week. One-third of all respondents denied having a regular physician, increasing the difficulty of getting timely access when necessary.

Many men are less likely to perceive health problems than women. Courtenay (2002) suggests this is due to a sense of invulnerability to health risk, when in fact men are frequently at much higher risk. Even with a physician recommendation, men are less likely than women to change their diet to prevent further health problems, to take medications as prescribed or to attend clinics for preventative therapies such as flu shots. Men often perceive health to be controlled by luck or chance, rather than assuming personal control and responsibility for health-maintaining behaviors (Courtenay, McCreary & Merighi, 2002). Depending on others to attend to health needs is evidenced by the inverse relationship of male morbidity and mortality to social network support, particularly marriage. Keller & Henrich (1999) state that social support is well-documented to be protective for men from all kinds of diseases and fatal outcomes.

Courtenay (1998) states that women not only have more frequent contacts with the medical system, but women receive more physician time as well as more detailed answers to their medical questions. Bird & Rieker (1999) suggest that as a result of early and regular encounters with health care professionals, women are more likely to ask direct questions and experience longer interactions. Seymour-Smith, Wetherell & Phoenix (2002) interviewed a small sample of outpatient clinic physicians and nurses, finding consistent beliefs of 'what men are like'. In the health promotion environment consistent behaviours are expected; the woman's role is that of the caretaker for the child-like man who is incapable of caring for himself. Within these interviews, male helplessness was viewed as expected and entertaining behaviour. Clearly, both health professionals and patients subscribe to the premise that men have less use than women for health care information.

Doyal (2001) advises that health promotion campaigns are targeted towards an exclusively female audience. As a result, men often have less health knowledge about common concerns such as cancer, sexually transmitted diseases and heart disease. Men are often unfamiliar with appropriate screening tests and common presenting symptoms of disease; Fullerton, Lantz & Robins Sadler (1997) state that health care professionals teach 86% of women breast self-examination but only 29% of men receive information on testicular self-examination. There are well-established Canadian screening recommendations for colorectal and prostate malignancies with simple tests such as routine fecal occult blood test, sigmoidoscopy (Health Canada, 2002), digital rectal examination and serum prostate specific antigen (Feightner, 2003). Lantz, Fullerton & Harshburger (2001) showed that even when screening tests for colorectal cancer were

recommended and scheduled, male compliance rates ranged from only 15 – 33%. Lack of information, delayed assessment by a physician and poor adherence to recommendations contributes to advanced disease at diagnosis and poorer survival outcomes. Reagan (1997) suggests that nearly a century of public health campaigns advising women that cancer is their particular health concern and responsibility is reflected in the beliefs and practices of both the health care practitioner and the lay population. Health information must be presented to a male audience in a way that is sensitive to the psychological difficulties and social challenges experienced by men.

Courtenay (2000b) indicates that feminist scholars were first to identify gender issues in health care, noting the absence of female participants in clinical trials and the problem of defining male parameters and male health resource utilization as the 'gold standard'. The attention to female health issues has greatly benefited women's health promotion overall (Stewart, Eastlick Kushner & Spitzer, 2001), however, the statement 'gender and health' is now almost exclusively associated with 'women's health'. Meryn & Jadad (2001) acknowledge this and advise that research must be focused on understanding men's beliefs and motivations in order to develop acceptable health promotion strategies. Porche & Willis (2004) call for a male health movement to coordinate fragmented initiatives, develop male-specific health promotion/disease prevention programs, promote gender-specific research efforts and coordinate mens' health outreach programs.

Masculinity and Illness

When a man experiences major illness the emotional effects are often significant (Charmaz, 1995). For the man who ascribes to hegemonic masculinity, illness reduces

his status amongst other men, alters his power relations with women, and negatively impacts all other areas of his masculinity. Helgeson (1995) states that men more frequently depend on their careers and role as breadwinner rather than on their relationships with others. If the man must cut back or retire from work, his gender role is threatened by his inability to maintain his social status and sense of achievement. Recovery from illness may require him to stop driving or attend therapy sessions. For a traditionally masculine individual, being dependent on others for transportation or care can be extremely stressful (Helgeson, 1995).

A healthy male physique embodies the socially valuable characteristics of toughness, competitiveness and virility (Gerschick & Miller, 1995). The loss of physical strength that may be a temporary or permanent effect of illness is a major threat to male gender identity. Men with permanent physical disabilities are often perceived by society as weak, passive and dependent. Gerschick and Miller's (1995) interviews with 10 mobility-impaired men highlighted the participants' lifelong struggle with the stigma of their physical limitations and the impossibility of achieving North American society's definition of masculinity.

Further research in the area of male coping with illness is warranted for practitioners to understand what interventions men consider useful and socially acceptable. It would also be important to understand ways in which chronically ill men redefine their value as men to themselves and their significant others.

Men and Cancer Experience

Nicholas (2000, p.27) emphasizes that 'more men than women get cancer, more men than women die from cancer and men usually adapt less well than women after a

cancer diagnosis'. Indicators of good adaptation are considered to be continued involvement in daily life activities, minimally disrupted life roles and manageable emotional distress. Zakowski et al. (2003) states that emotional expression has been associated with variety of mental and physical health benefits among breast cancer patients, however, these findings are difficult to apply to men, for the participants in her study were exclusively female. Moynihan's (2002) review of psychosocial oncology publications between 1984 – 1998 indicated that men are overwhelmingly underrepresented and marginalized. It is difficult to establish what factors prevent male participants from entering psychosocial studies. It could be personal factors, health care professional perceptions or the characteristics of the studies that contribute to men's under-representation. Women with breast cancer may have set the benchmark by which health care professionals define proper psychosocial adjustment amongst cancer patients of all types. Research projects specifically targeting male populations and multiple tumor sites are critically necessary to explore varied psychosocial needs of cancer patients.

Keller & Henrich (1996) and Volkers (1999) suggest that a cancer diagnosis might be considered an attack on male identity, associated with strength and invulnerability. Emotional expressiveness is discouraged within traditional male values (Nicholas, 2000). Men tend to rely on themselves, withdraw socially and try to talk themselves out of depression (Courtenay, 1998). The need to ask for psychosocial help further threatens the male sense of masculinity and potentially leads to increased distress and loss of self-esteem.

Vaartio, Kiviniemi & Suominen (2003) interviewed male survivors of various malignancies. Although the participants described overwhelming depression and fatigue

during and after therapy, none of the men sought the help of professionals or support groups for their emotional problems. The men either coped with their concerns alone or shared their worries with their wives. Reasons for these choices were not explored in this study. Kelsey, Owens & White's (2004) observations of prostate cancer patients receiving radiotherapy were similar, in that men did not hesitate to share bad news with their wives, but that it took time and courage to share with other family members and friends. These methods of coping need to be considered by providers when developing health information and services acceptable to men.

Hann et al. (2002) examined depressive symptoms in both male and female cancer patients, finding that while a large social support network was beneficial for females, there was no improvement in male depression. Nicholas (2000) states that men are unlikely to provide, receive or seek out social support compared to women. Keller & Henrich (1996) suggest that men confide and rely heavily on one person, usually their marital partner. The researchers examined married cancer patients, finding that men relied mainly on their wives and reported improved marital relationships since illness. Female participants reported relying less on their husbands and more on social support from others within and outside their families. Harrison, Maguire & Pitceathly (1995) suggest that women are already familiar with sharing emotional experiences with friends and family and continue to rely on these established personal assets when difficulties arise.

Men's relationships with other men are often focused on physical activity rather than emotional sharing (Helgeson, 1995). Close friendships are frequently difficult between men, for open displays of affection make men potential targets for homosexual

comments. Competitiveness between men further restricts disclosure of vulnerabilities or concerns. These social limitations placed upon men's relationships with each other also limit opportunities for emotional intimacy or benefiting from another man's perspective and experience. As a result, men often look to women for self-disclosure and emotional work.

Support groups have a longstanding tradition for women who have survived breast cancer. For male malignancies such as prostate cancer, support groups have been developed but are poorly attended (North, personal communication 2004). Kiss & Meryn (2001) state that men who attend support groups prefer to share informational resources, whereas women who attend support groups prefer to debrief their illness experiences. Helgeson (1995) states that support is composed of three parts: instrumental support including financial and material resources; informational support including technical information and advice; and emotional support providing opportunity to acknowledge and share feelings. It is possible that men prefer a different mix of these supports compared to the majority of women, and that these differences explain the findings. Shapiro, Coyne, Kruus, Palmer, Vaughn, & Malkowicz (2004) surveyed prostate cancer patients' interest in support services, finding that while 70% of men would have appreciated informational support such as written materials or the opportunity to ask questions of the oncologist, only 22% expressed interest in receiving any form of emotional or psychosocial support. It is not known if the preferences of this sample of older, married and well educated prostate cancer patients are indicative of the preferences of men experiencing other malignancies.

Gordon (1995) undertook in-depth interviews with men who had experienced testicular cancer. All participants identified similar initial reactions such as fear of death, disfigurement and suffering, largely resolved once full recovery was made post-surgery and the men learned the cure rate was nearly 100%. The effect of the diagnosis on the masculine identity of these men was not as significant as expected, as they were able to recover very quickly and return to all their pre-diagnosis activities (including sexual intercourse). The participants who were married prior to their diagnosis reported that the continued emotional support and physical intimacy that their wives provided made coping with the changes to their bodies significantly easier.

Gordon reported that that the participants framed their experiences from two different perspectives: reaffirming a traditional version of masculinity or adopting a less traditional view of masculinity. Those men who adopted a traditional approach felt the diagnosis was a challenge or test of courage, that they had to fight to get back to all normal activities regardless of the cost. Maintaining a strong and silent approach to those around them helped these men maintain a sense of masculinity but may have also prevented them from receiving emotional help. Within this group, Gordon found the men continued to experience long-term concerns about a less desirable body image.

The men considered to have adopted a less traditional approach felt that they were more emotionally expressive, more concerned about relationships with those around them and were more empathetic since their diagnosis and treatment. These men reported feeling better about themselves and life in general. Gordon (1995) concluded that for men facing testicular cancer, it was important to be able to maintain a satisfactory self-definition as a man. Self-definition could be either a traditional perspective or a non-

traditional view of masculinity. Further research among men who have survived other types of cancers may be helpful to provide additional knowledge about different coping strategies men use.

Male Breast Cancer

Health Canada data (2004) reported breast cancer to be the most frequently diagnosed malignancy in women, accounting for about 30% of all new cancer cases annually. These estimates indicate that 21,400 cases will be diagnosed and 5,300 women will die of breast cancer. Male breast cancer is less common and accounts for less than 1% of all breast cancer cases (Hayes, 2002), with Canadian estimates at 145 cases for 2004. However, a recent report by Giordano, Cohen, Buzdar, Perkins & Hortobagyi (2004) indicates that male breast cancer rates are increasing in North America. Her review of breast cancer cases from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) database showed that incidence rates increased from 0.86/100,000 in the 1973-1978 period to 1.08/100,000 in the 1994-1998 period. This finding was unexpected and refutes the previously accepted theory that male breast cancer rates are stable. The reasons for these increased rates are unknown but warrant investigation (Giordano et al., 2004).

The prevalence of male breast cancer increases with age, with 60 being the average age at diagnosis (Ravandi-Kashani & Hayes, 1998). Given the infrequency of male breast cancer, possible causes are difficult to explore. Hormonal alterations are thought to be a contributing factor and could be caused by changes in testicular function from undescended testes, testicular injury, late puberty, infertility, schistosomiasis, or liver cirrhosis. Obesity is considered a contributor to male breast cancer by causing increased

serum estrogen levels (Giordano et al., 2004). In fatty tissue, testosterone is converted to estradiol and androstenedione to estrone by a process known as aromatization (Hsing, McLaughlin, Cocco, Co Chien & Fraumeni, 1998). Environmental or occupational factors that are thought to increase men's risk of hormonal changes include exposure to magnetic fields or radiation and occupations such as steelworking where chronic heat exposure might suppress testicular function (Ravandi-Kashani & Hayes, 1998).

Potential genetic influences on the development of malignancy have attracted considerable interest. The presence of a male breast cancer case within a family having known female breast cancer cases suggests a 60 – 70% chance of the family carrying the BRCA2 gene (Giordano, Buzdar & Hortobagyi, 2002). Data from the series of Rayson et al. (1998) suggests that 15 – 20% of male breast cancer cases have a positive breast cancer family history; however, the majority of male breast cancer cases remain sporadic events.

Some practitioners believe that the prognosis for men with breast cancer is worse than that of women. However it is difficult to establish the true reason for this (Donegan, Redlich, Lang & Gall, 1998). As men tend to be older at diagnosis, other co-morbidities are more likely. Other possible reasons could be the lack of practitioner knowledge of male breast cancer or a reluctance of the man to attend a physician until the disease is in advanced stage. Given the major amount of media and medical attention to female breast cancer, the risk to men is virtually unknown by both health professionals and the lay population. If a clinician does not perceive concern or attend to the male breast during routine physical examinations, neither will the patient (Fullerton, Lantz & Robins Sadler, 1997).

Large case reviews by other practitioners reveal different findings. Goss, Reid, Pintilie, Lim & Miller's (1998) matched cases of men and women attending a large Canadian cancer center, showing that when matched for TNM stage (tumor size, lymph node positive/negative, and distant metastases) the clinical outcome was very similar. These observations are supported by Giordano, Buzdar & Hortobagyi (2002), whose review also indicated that stage and age-matched men and women have equivalent prognosis. As with female patients, tumor size and axillary lymph node status at diagnosis are the most important indicators of survival for male breast cancer patients.

Treatment recommendations are based on the assumption that that the disease course of male breast cancer is similar to that of females, however phase II and III breast cancer therapeutic trials do not accept men as participants. There remains a major lack of information to assist men or health care practitioners manage this uncommon diagnosis (Giordano, Cohen, Buzdar, Perkins & Hortobagyi, 2004).

Surgery is the primary treatment for early breast cancer. Men have less breast tissue so a simple mastectomy is the most common surgical intervention, with axillary lymph node dissection or sentinel lymph node biopsy (in centers with specialized equipment and qualified surgeons). Giordano, Buzdar & Hortobagyi (2002) recommend that men be considered for adjuvant chemotherapy by the same risk categories as women. Men with pathologically higher-risk disease (lymph-node positive, larger tumor size, higher histologic grade, lymph/vascular invasion, cerbB2 positive) would be expected to receive a similar magnitude of benefit from chemotherapy. As 80% - 100% of male breast cancer cases are hormone-receptor positive (Hayes, 2002) as compared to 60% of female (Volm, 2003), endocrine treatment has been the cornerstone of adjuvant therapy

for male breast cancer patients. The anti-estrogen tamoxifen is routinely recommended for five years duration (Hayes, 2002) for the significant survival benefit similar to that of female patients.

Radiation therapy is not routinely prescribed for women or men after mastectomy with axillary lymph-node negative disease (Scarth, Cantin, Levine, et al., 2002). It may be recommended for both men and women with high-risk features such as large tumors, a high proportion of positive axillary lymph nodes compared to the number resected, lymphatic or vascular invasion and close or positive surgical resection margins (Volm, 2003). Depending on the male case, radiation therapy would be recommended to the chest wall, internal mammary chain, supraclavicular lymphatics, or the dissected axilla as appropriate (de los Santos & Bucholz, 2000).

Bunkley, Robinson, Bennett & Gordon (2000) suggest that men diagnosed with breast cancer may experience many serious psychologic issues. Men may perceive themselves as less manly by having a woman's disease, particularly if they have a history of testicular problems. Men may also feel isolated with a rare malignancy normally affecting women and be less likely to seek or receive support. Some men might experience distress related to post-treatment physical changes including loss of the breast, changes to the appearance of the male chest, lymphedema or decreased arm strength.

Experiential research in male breast cancer

One qualitative study exploring the experiences of men with breast cancer was found in the literature. France, Michie, Barrett-Lee, Harper & Gray (2000) interviewed six men in Wales who had completed chemotherapy or radiotherapy. Personal interviews were conducted following to a list of established questions and audio-taped in the

patients' home. When a spouse was present, she was invited to comment. Although the number of participants was small, common themes emerged among the six men. All participants expressed shock with the diagnosis of a breast malignancy, for none of them knew that men could have breast cancer. Four of the six men described concern about the stigma of having an essentially female disease, and three men stated that they were reluctant to go without their shirts. Three participants voiced theories about causative factors and possible toxic exposures. None of the six men received any information specific to male breast cancer or treatment approaches. Two men received written information about female breast cancer. Emotional support and counseling was not available to these men by formal means. Support came from their spouses or a friend.

These same men were later involved in focus group discussions along with women with breast cancer and breast health care professionals (Williams, Iredale, Brain, France, Barrett-Lee and Gray, 2003). The men indicated that they would have appreciated the opportunity to speak with another man with breast cancer, that a men's-only breast support group would have been helpful, and that a paragraph dedicated to male breast cancer within general breast cancer information packages would have been appreciated.

Whether or not North American men might have similar experiences as this small sample of European men is unknown. I elected to utilize unstructured interviews, for Canadian men might identify different experiences or concerns than European men. Unstructured interviews and hearing their individual stories would provide the opportunity and the opening to understand their experiences.

Chapter 3 – Method

Brink & Wood (1998) suggest that qualitative designs are necessary to explore topics where virtually nothing is known about the phenomenon or experience. Qualitative designs assist in examining gender biases and how people experience social norms and standards. Koch (1998) proposes that careful systematic examination of human experiences or stories has the potential to advance understanding.

Stories

From early times humans have communicated through story. Stories are the primary means by which human experiences are made meaningful (Polkinghorne, 1988). Communicating through story is a natural impulse, whereby we express our emotions, our relationships and identities (Priest, Roberts & Woods, 2002). In our stories, we create an order and orientation in the telling of life events, as well as learning from and gaining a sense of perspective by the act of telling and re-telling.

The story brings the diverse elements of experience, thoughts and feelings together, connected by a central theme and purpose. It is not merely a way of describing our lives, but the means by which we organize the experiences and the information we encounter (Gilbert, 2002). We may create order from disorder; we may establish meaning in a potentially meaningless situation.

The construction and telling of stories has a social basis. Gilbert (2002) states that we create and explore stories in concert with the interested party or listener. Gergen and Gergen (1988) suggest that relationships are lived out in narrative form; that the story serves as a critical means by which we make ourselves understood within the social world. The answer to 'who' we are takes shape in the stories we tell about ourselves

(Hinchman & Hinchman, 1997). Our personal stories are created as we describe our present choices and actions in the context of our imagined futures.

Polkinghorne (1988) suggests that we understand our existence as a single unfolding and developing story; that we are in the middle of our stories with no knowledge of the ending. He describes the self as a "configuration of personal events into a historical unity, including what has happened and anticipation of future" (p. 151 – 152). The life story as told is a re-telling of the life as lived, open to editing and revision. The story is a representation or interpretation of the lived experience, subject to change and colored by experience (Gilbert, 2002).

The story form

The story is a form of expression, most often verbal and organized into coherent, meaningful themes (Polkinghorne, 1988). Gergen and Gergen (1988) describe the story as an ordering of events, as well as the selection and telling of events considered relevant to the goal or story. Sandelowski (1994) submits that each story has structure and shape: an abstract (what the story is generally about), an orientation (who, where, what, when, why), some complicating action ("and then such-and such happened"), an evaluation (so then what finally happened), and a return to the present time (p. 25). The ending cannot be predicted, but holds surprises, coincidences and encounters to sustain the listener's attention. She explains that the story is a representation of the experience as told at a particular moment in time, different with each telling and with each witness. The strength of story lies in the way the experience is drawn out and how the meaning is conveyed (Martin-McDonald, 1999); it is the meaning-making that is central to the human experience.

Story or narrative in health research

Bruner (in Sandelowski, 1994) advises that narrative knowledge is just as essential as paradigmatic knowledge (the knowledge gained through science) to make sense of the world. She refers to the growing use of narrative analysis with origins in philosophy, anthropology, sociology, psychology and socio-linguistics, ethnomethodology and literary criticism. Polkinghorne (1988) states that narrative research can produce a description of the events that individuals or groups use to make their lives meaningful. He suggests that narrative research may describe the views or stories already held by individuals or groups (descriptive) or may explain through narrative why something happened (explanatory).

Koch (1998) describes story telling in nursing as a powerful vehicle for communication as well as a means for creating empathic forms of understanding. Nurses bear witness to intensely personal and emotional human experiences in their everyday practice. Koch advises that listening to voices of patients through story will reveal means to improve practice, as well as making nursing practice visible.

Sandelowski (1994) looks back to the evolution of health knowledge, reflecting that personal biographies have long disappeared and have been replaced by the medical history, the story from the perspective of a professional stranger. She urges the return to a time when patients' stories were important to the clinician's description of the disease state; to a time when observing patients did not preclude seeing them; and to a time when listening to patients did not preclude hearing them (page 24). Sandelowski applauds the sensitive practitioner who seeks to describe what is unique in *nursing*: the reconciliation of scientific and humanistic imperatives, the preservation of wholeness and health of

patients as they struggle with illness and the depersonalizing experience of medical science and technology. She advises that through narrative research, nurses will discover (or re-discover) knowledge, uncover the wisdom embedded in practice, and recover the art of nursing. Through narrative, Sandelowski believes the nurse will learn the nature and function of stories for patients, the relevance of story in the nurse's diagnostic and healing function and the significance of personal stories in a holistic nursing practice.

Pateman (2000) argues the importance of research methods that encourage equality of the researcher and researched, provide opportunities for social change and empowerment as well as opportunities for giving voice. He discusses the development of feminist research methods and postmodern approaches to knowledge in the last decades, feeling that these methods are conducted *with* people, in contrast to rigid "masculine" research methodologies conducted *on* people. Pateman emphasizes the value of narrative as a holistic method of exploring the experiences of disenfranchised groups whose stories are not told, whose stories are not considered important. Martin-McDonald (1999) agrees, advising that story brings voice to the experiences of minority and marginalized groups including those affected by society's views on gender, sexual orientation, race and class.

Stories of illness from the individuals' perspective

Arthur Frank (1995) describes serious illness as a life-event that precipitates the loss of the 'destination and map' (p. 1) that had previously guided the individual's life. By hearing themselves tell their stories, by witnessing the reactions of others and by experiencing their stories being shared, people with illness learn to think differently about themselves and their place in the world. The disruption of the previous life invalidates the context of the old stories and prompts the need for new ones. Frank suggests that the

body is at once the cause, topic and instrument of whatever new stories are developed and told. These embodied stories have personal and social aspects. Stories reflect the personal aspect by giving voice to the body, so the now-changed body can become once again familiar. The social aspect of stories includes the act of revealing oneself to another, whether the witness is immediately present or not. Frank (1995) states that people do not consciously make up stories for themselves; rather, the telling is shaped by all the expectations formed by society, culture and other stories witnessed by the storyteller in the past. The story follows the formal structures of narrative, with conventional metaphors and imagery as well as conforming to standards of what is and what is not appropriate to tell. Frank (2000) also argues against authors employing a strict definition of either a 'story' or a 'narrative', for no one says, 'I'm going to tell you a narrative about what happened'. For the purpose of this project the terms 'story' and 'narrative' will be used interchangeably.

Narrative research is extremely useful in exploring and understanding the effects disease has on the individual and the significant others in their lives (Overcash, 2004). Stories are inseparable from the lives of the respondents and as the stories are told and heard, deep understandings develop. The stories provide meaning to past events and actions of the respondent's life, regardless of whether or not the story is a completely factual rendering. Through the narrative, the researcher may understand the meaning of the experience from the perspective of the respondent. Additionally, Overcash (2004) suggests that the teller of the story may experience therapeutic benefit while giving voice to the experience to an interested audience.

Sample

Qualitative research frequently relies on small sample sizes with the intent of studying a human experience or phenomenon in depth and detail (Tuckett, 2004). Research approaches directed toward in-depth examination of human experiences often include about six participants (Sandelowski, 1995a). In the quest of obtaining this rich data, the sample is derived purposefully rather than randomly. Coyne (1997) describes the starting point of purposeful sampling as selecting those individuals whose knowledge or characteristics fit the aim of the research; age, gender or health status are examples of such characteristics. As the participants are interviewed, those individuals considered 'good informants' (Leininger, 1994) are identified by the researcher. A good informant is one able to meet the informational needs of the study, as well as being articulate, reflective and willing to share his experiences with the interviewer.

Ethics approval was sought and obtained from the two relevant ethics review Boards. Approval was gained June 6, 2005 from the Health Research Ethics Board (HREB) Panel B of the University of Alberta / Capital Health Region of Edmonton (Appendix A). Reciprocal approval was gained from the Research Ethics Board of the Alberta Cancer Board on June 22, 2005. A list of potential participants based on the inquiry terms 'breast cancer', 'male' and 'alive' was generated by the Alberta Cancer Board Cancer Registry. The sample thus included men greater or equal to 18 years of age with a diagnosis of in-situ, invasive or metastatic breast cancer. The approval of the Health Research Ethics Board included the stipulation that the researcher must not directly contact potential participants; it was expressly stated that the men be mailed a consent form and information to contact the researcher. Therefore, the Cancer Registry

mailed out an invitation letter, consent form and the researcher's business card to the 128 potential participants the week of July 8, 2005. As stipulated by the Health Research Ethics Board, I was not included in this process. Thirty-one forms were returned undeliverable; it was therefore assumed that 97 invitations were received. As the forms were in English, the respondents had to be English-speaking to consent to participation. Twenty men returned either signed consent forms or contacted me by telephone indicating they wished to participate. As I had no involvement in the recruitment procedure as well as not knowing how many participants would need to be interviewed to find good informants, I elected to conduct interviews with all twenty men. While this number exceeds what is considered conventional for such a project (Sandelowski, 1995a), I believe that interviewing all the men honored their desire to contribute and provided them with the opportunity to contribute to new knowledge.

Interviews

Unstructured interviews are advantageous in that the focus is on the participant's conception of the experience rather than the pre-conceptions held by the researcher. Brink (1989) advocates the development of a general opening question to help the informant take the researcher back into the experience. Rather than an exhaustive list of questions, four probing questions were developed (Appendix B) with the intent of stimulating a more lengthy description of the experience and most importantly, encouraging the account of what the respondent considered important (Overcash, 2004).

From his study interviewing men who had undergone transurethral prostate resections, Pateman advocates a 'cosy chat' approach, being non-directive and encouraging the involvement of other family members (2002). The experience of

Moynihan (1998) suggests that men be given the opportunity to talk in a place of their own choosing that is safe and non-threatening. Once the participant agreed to be interviewed, I asked him to identify where and with whom he would be most comfortable. Experienced researchers (Gordon, personal communication July 2004; Charmaz, personal communication July 2004) advise that having a spouse present does not inhibit the interview but rather added richness to the data with added information. I am middle-aged female with a background in nursing; authors suggest that men may respond more comfortably with a female researcher (Pateman, 2000; Schwalbe & Wolkomir, 2002) and expect improved communication and sympathy styles (Mast 2004). Homophobia or machismo undercurrents between a male interviewer and male participant could inhibit rather than facilitate disclosure.

Twenty unstructured interviews were carried out between the dates of July 31, 2005 and October 2, 2005 across the province of Alberta. These audio-taped interviews were conducted at a location of the participants' choosing, most frequently at the participants' house. If a spouse was present, she was not discouraged from commenting. Two men attended the cancer center for interviews in my private office, one man came to my home, with the rest of the interviews occurring at the participant's home. One participant had moved to another province; this interview was performed by telephone and audio-taped in entirety.

After an explanation including my background and the purpose of project, written informed consent was obtained. I initiated the interview with the question: "*When did you first know something was wrong?*" The participant then began to tell his story, describing the thoughts and experiences he considered important. Clarification of meaning was

sought during the telling. Other questions and areas of discussion were generated based on the participant's disclosure. The interviews were 1 – 2 hours in duration depending on the volubility of the participant. The audio-tapes were transcribed within 48 hours of the interview.

From interview to story

Martin-McDonald (1999) states that narrative analysis is developmental; the researcher must work to represent the lives of the participants by describing the 'how' and 'why' of story interpretation. She advocates a postmodern approach where the researcher is but one of many potential listeners of the participants' story, as the participant leads the listeners through the experience.

Emden (1998a) describes a method of 'core story' creation, where the researcher aims to reduce a full-length story to shorter forms to aid the analysis process. In order to retain a greater sense of the whole story and preserve the content and structure as laid out verbally by the participant, she recommends the researcher first read the transcript several times. Interviewer statements are deleted, the remaining text is read for sense and further detracting words and phrases are culled from the text. The researcher re-reads several times to identify themes coming through the story. Emden (1998a) suggests the re-arrangements of sub-plots to create a core story, however, other researchers argue against this, recommending the order and significance of events as told by the participant be preserved (Martin-McDonald, 2000).

All twenty interviews were read and re-read several times, as described above. My questions and comments were removed, as well as repetitive 'uhms' and other language fillers. The order the respondent provided when asked the question 'when did

you first know something was wrong?', as well as questions arising from his experiences were all preserved. Long pauses where the respondent found it difficult to talk about the experience or the respondent cried, leaving long pauses in the audio-tape were also preserved in the transcript.

Notations of my observations and experiences during the interviews were maintained, in addition to the audio-taped recording of each interview. These remain locked in a secure office at the Cross Cancer Institute, Edmonton Alberta. A log of all travel across the province, including kilometers and locations was also maintained during the interviewing period.

Bailey (1996) states that narrativists refer to validity and reliability with the terms *trustworthiness* and *credibility*. She suggests that the researcher allows the reader to judge the trustworthiness and authenticity of the work by visibly describing the research process, allowing for scrutiny. Sandelowski (1993) advises that the researcher imbues trustworthiness in the research product by making the research process as transparent as possible. As described with the process of transforming interviews to stories, I have altered the participant's text as little as possible. My goal has been to preserve the complete meaning and intent of the story as presented by the teller.

Chapter 4 – Four Stories

From the 20 interviews conducted, the stories of four articulate informants are presented. Their stories are rich and describe many of the experiences shared by other participants. To further support the analytical and interpretive credibility of this narrative research project (Koch, 1998), the remaining 16 stories are included in Appendix C.

Eric's Story

Two years before, I knew something was up but had no idea what it was. I had taken my oldest son in to a hockey game in the City and had on a brand-new T-shirt with an embroidered logo on the left side. Halfway to the City I was so irritated on the left side, I had to stop and change my shirt, and it just kept going from there. I remember having to go into the first aid room at work and getting cotton batten and a band-aid to put on top of the nipple area. Just the shirt touching it would drive me crazy. I went to the doctor 4 times - he kept telling me as you get older your body changes, and it's nothing. It got to the point it was getting embarrassing going back to the doctor, because I was wasting his time - that's how I was made to feel. This just kept going on, and I learned to live with it after while. One thing I did notice was that the nipple on the left side was rock hard compared to the other side. You know your own body - I knew it was different.

So, things went on for 2 years like that. One morning in late February of 2003 I had a shower. When I got finished in the shower I went to wipe the mirror to have a shave and I was covered in blood on the left side. I thought *"this isn't normal"*. I made an appointment to see a doctor – in Town you make an appointment and it's almost 3 weeks before you can get in anywhere. When I did get in, again I was telling the doctor, and you could see him roll his eyes - he wasn't interested. But when I took my shirt off, he had a look and knew right away there was something wrong. This was a Thursday, and he booked me for X-rays and to see the surgeon the following Monday. I didn't think anything of it at the time, that it might be a biopsy or whatever. When I went in to see the surgeon, he saw me and his exact words were "Holy Crap!" It kind of startled me! (*laugh*). I had never met this guy before. He left the room and came back in with a nurse,

saying "I want you to go with this lady". This was 9 o'clock in the morning and by 3 o'clock in the afternoon I finally said "somebody tell me what's going on here – I've been for bloodwork, I've gone through everything." Nobody had said a thing. I've never ever not shown up for work without phoning. I had said I was at the doctor, but no doctor appointment takes this long. One lady said, "sit down I want to talk to you….you're having surgery tomorrow morning. I want to prepare you for surgery". And I said, "surgery for what?' And at first she said, "we're doing a mastectomy". I said, "for what?" She said, "there's no way they're going to save the nipple, but they're going to take a sample and find out what's going on." It all happened so fast I didn't have a chance to think about it. So I went in and had surgery. I was out of there in a day – I stayed one night and that was it.

So I had to go back for results and even that was a bad thing. They kept saying come back, come back, but there were no results. Finally, I was sitting there one Monday morning. The doctor came in and he left, then three people came in. I'm thinking to myself "this isn't good….three people!" So the one nurse tells me they've called a cab for me. And I said, "called a cab? What are you talking about?" She says, "Well you DO have cancer". I said, "I'm not taking no cab….I drove here, I'm driving out of here". She says, "well you're kind of taking it nonchalantly". I said, "Well, I just got the news….maybe it will sink in later. It's not the end of the world, here". She says, "you'll have to go through chemo and all the stuff. You're booked for surgery again tomorrow". I said, "No, not tomorrow, I'll go Wednesday". I said, "because I'm going home, I've got things to do and I'm getting drunk tonight!!!" (*laughs*). So I went in Wednesday and they did the surgery. When I went for results after that, I remember the doctor saying "we

got it all, there's no lymphatic invasion. Everything's fine, you might need 5 radiation treatments". So I thought this was great.

So I went to the Cancer Clinic in the City to see the Oncologist. There was a nurse who kept reading my file. I was saying "that's not me" because she had totally different information that what I was told back at the Town. She left the room and was rather embarrassed. She came back in and asked "you're Eric?" And she said, "This is your file. The reason they didn't have any lymphatic invasion is because when they did the surgery, they didn't take any lymph nodes". Mine were deeper than someone else's, I guess, because they did the exact same surgery. The Oncologist explained it very well. The surgeon did the procedure as he should, because the lymph nodes aren't visible. After some tests, I did have lymphatic invasion, and it had spread. It had gone from a level 1 to a level 4 cancer. They told me what they recommended, and I said "go for it", because I didn't really have any other choice. I had a family and had only one thing I wanted to do, to get better.

I didn't like the idea of chemo, and I'm kind of glad I didn't know a whole lot about the chemo before it started, 'cause I didn't like that *at all*. I went to the chemo teachings at the Cancer Center, and they gave you a lot of information. I guess was information overload at first, but as you go into it, that information came back, because it was very important. The nurse had said "you won't be able to sit down and eat a big meal, you probably will never be able to sit down at mealtimes with someone else, your schedule is going to be so wonky, but eat 10 times a day - eat small bits". And I remembered the Oncologist said, "if you feel like a milkshake, go for it. Just keep up your eating habits" and I did. I forced myself. I had to learn, because each cycle I had

exactly the same side effects each time. I wrote things down, what day this worked, what day that worked – for example, I could drink tomato juice on the 4th day, but I couldn't drink it on the 5th day. I kind of had things prepared, planned how I could do it.

They gave me a book to chart my memories, but I am not one to remember that kind of stuff. I remember up here (*points to head*) very well, but I had one focus, one thing I wanted to do….to improve. That was just writing negative stuff down, and I was not into that at all. I don't know if support groups would have been helpful for me. I didn't think I needed to talk to anybody. I had one person - I should say I had someone I could talk to. She used to work for me in another town and had exactly the same cancer. It was helpful to find out, because all the side effects that I went through, I would wonder "does everybody experience these side effects?" and she had exactly the same side effects.

The one side effect that bothered me the most was the dreams; I had the most vivid dreams that drove me crazy. From about the 5th to the 9th day I'd have 4 days of dreams and have the same dream every night. You know, it would just carry on. Usually you wake up and can't remember the dream. Well, I could remember these - they were just - *unbelievable*. She'd say, 'I had exactly the same thing'.

But I'm not the kind of person to just phone someone. I'm not the type of person to get swallowed up and be depressed. I'll phone and ask for information and move on. I've even helped someone I don't even know. A friend of mine in Manitoba had a friend who had has gone through treatment. I had no problem picking up the phone and seeing how they're doing. Because I think, that the number one thing - that you've gotta have the right mind-set, you know, to get through it. Because, I found it's harder on the

spouse. She had no control; I have control over me, but she has no control at all. You've got to keep them informed what's going on, but I think it would be harder on me if she had the cancer, because, again I'd be out of control. But I had all the control in this one. And I'm very stubborn, and if I have my mind set to do something, there's nothing that sways me off it.

I read all the stuff I got from the Cancer Center, like the side effects and stuff. That was helpful, what to do, what to eat, how to keep your energy up, things like that. A lot of those things helped. I had to phone the Cancer Center several times, when different things that happened. There was a couple times that I couldn't stop the vomiting after a chemo treatment - it was going on way too long. And the people at the Cancer Center would help you out and give you pointers. I found it calmed me quite a bit, 'cause they were so good down there. I enjoyed dealing with them. And the same with the radiation part of it. They give you a pamphlet and go over what to expect, and if you need help, here's the phone number to ask. It was all very good.

I found that not a lot was known about male breast cancer. They'd say, "we're going to try this, but we have no information on it". Like tamoxifen, when I was done all my treatments, "we have no data on men with tamoxifen". I checked the Internet, and everything was about women. Everything about breast cancer is about women. I took tamoxifen for just about a year, and during the last part of it I started getting really sick. I'd be throwing up every morning until at least until ten o'clock. I still worked, but it was a rough start to every day. You know, I could shake it usually by noon, and if it wasn't gone by noon I'd have it for the day. I talked to the people at the Cancer Clinic about it. They'd say "no, it shouldn't be the tamoxifen", I talked to my doctor about it; he said "no

way, it's not the tamoxifen, give up the vitamins and other stuff". Until I talked with another Oncologist and he said "it's the tamoxifen". Then he put me on Arimidex; but that one there, I wouldn't recommend that for anybody. I found it was so bad for mood-altering, that it's actually dangerous. I was mad at my kids for stuff that was stupid. Like my son wanted to borrow the truck to take his girlfriend home, and I knew that he'd usually do that, so what's the big deal? But I was ready to rip his head off for using it. Then I said "that's enough, I'm not taking that stuff anymore".

But I did experience what women go through with menopause with the tamoxifen with the hot flashes. Holy mackerel! Like almost pass out! I can sympathize with them for that! (*laughs*) I was worried about driving, because when they say you get hot flashes and feel faint - I'm telling you, I felt that if I tilted my head backwards I'd just fall down, that's how faint I felt. It didn't last long, 2 or 3 weeks or so, but kind of alarming to drive like that.

Since the diagnosis I spend a lot more time with my family. Right up until the time I went into the hospital I'd work 900 – 1000 hours a year overtime. I still work some overtime, but last year I had 50 hours. I bank it and take it as time off. I don't take the pay anymore and I don't miss it. I'm not any less dedicated at my job, I just don't work the overtime. I spend a lot more time doing things; I've gone on ski trips with my son and different things with the kids that they're interested in. I find the overtime is not important anymore. I'm still pretty driven; before at work I was always striving for one notch better in the company. I'm not doing that anymore. It's more important to me to take a couple of those overtime hours and go to the lake – I'm not after that next position. At home, I spend more time with the kids, but I haven't really changed a whole lot. Some

people say it's a life-altering experience or whatever, but I haven't changed like that. What *has* changed is that we try to enjoy today more than we did before. I just bought a boat and a new vehicle. We still put away for our retirement, but enjoy our life while we still have it. Because I still have it in the back of my mind, I don't let it bother me too much, but I had it once - will it come back? That always is in the back of your mind. One thing about having cancer, you can't get life insurance anymore. You can't get a loan with life insurance. Another thing that you have to look at too is if you want to change jobs - will they cover you under their policy?

I never felt ashamed by having had breast cancer. The only thing I find that bothers me is that I'm a little self-conscious about the scar. I always wear a shirt - I guess I don't want to advertise it, but I have no problem talking to someone about it. I know a lot of people are shocked to know I went through it.

I don't know if I ever thought about the possibility of breast cancer. I wasn't totally shocked at the time, like "I never heard of this" so I guess I must have heard about it in the past. And I never did, once say "why me?" It happened – it happened. I used to be involved with a body shop. I painted for years and had isocyanide poisoning from working in the body shop. My family doctor got a book and was shocked at what kind of damage it could cause. Now, talking to the oncologist, she said it's very possible, but impossible to pinpoint what the cause really was. But it's possible. My father has leukemia right now, a blood disorder called myelodysplastic syndrome. They feel very strongly it's a result of isocyanide poisoning. So, there's so many factors out there but if that actually contributed to it, we don't know. When I first started painting, I would work in a booth in the summertime with a muscle shirt and a mask on. I remember going to

school a few years later. I remember they asked for all our masks, and every one of the guys put their masks on the table. The instructor came along and threw them all in the garbage. He said this doesn't stop even 1% of the isocyanates - none of us knew that. And that's what the paint companies are selling. They told us to get air-fed system, but it's still close to your eyes, your skin; there's all kinds of access into your body. So here you are now, wearing a full-face shield to cover your eyes, a Haz-mat suit with hoods, rubber gloves; when lots of times before in the summer I'd go in with shorts and a T-shirt, spraying a car and never thought anything of it. When you get out, of course you're covered in overspray. You just take paint thinner and wipe yourself down, and never think anything of it!

Going back, I wouldn't change anything. I've often said that, and people look at you kind of funny. I had cancer but I wouldn't change it because it's brought other things forward, it's brought the family closer. We've learned to deal with things a lot better. I wouldn't go back and change anything. You have to experience what life gives you in order to be able to move on and be stronger with it. My wife is very strong. We talked, because of course I never told anybody until after I sat down with her. When we talked, we decided to tell our kids first. At the beginning, she was very upset and teary. I had to prepare myself before I walked in there to tell her. If I'd walked in there like a basket case, it would have been worse for her. So I had to walk in, I had to prepare myself and …."OK" and put my game face on.

We decided that we were not going to change anything; we were going to continue doing things the way we were. Yes, there was going to be some financial changes, because I wasn't working. We told the kids to be prepared. We were both very

strong with it. My wife did things, she made homemade chicken soup for me, and I really found that helped me get through the chemo treatments. So she started to prepare meals for me for each one…she did her part. You know, we just made it happen. I guess we didn't put a lot of thought into it, we just dealt with it rather than making it an obstruction in the family.

That Christmas, I'd said to the kids, "this Christmas is going to be a tough one". I got paid through long-term disability through work, and it was less money. But Enid and I put a little bit away each month in a separate account. When I was going through radiation in the City before Christmas, I'd go to treatment at eight o'clock and I'd have the whole day to kill, six whole weeks. I can't sit around; I went and shopped and checked out bargains. The kids were amazed. I brought home snowboards - it was a Christmas that they had no idea was going to happen. They said to me they never noticed a big change. They did a card up for me, that it wasn't that they didn't care but they were able to get through the last nine months because of the way I was. They said they thought I was very strong, and the way I carried on - I did everything. Everybody did their part, they really did.

When you go through that, you're not producing at work, so are you productive at home? It does bother you, like, am I carrying my fair share of the load? So when I wasn't working, that was fine, that part I had to put on the back burner. But when Enid was working every day, she took on a few extra hours to help out, too. I felt as long as she was working, she shouldn't have to do any cooking, any cleaning, any laundry. And it may sound trivial, but I was so beat through the treatments. I'd use my day-timer and write a list of things to do each day, and she'd come home from work and supper would

be ready for her each day. She never had to worry about laundry or anything like that. That's not a real hard thing, if you plan it throughout your day. I felt, as I'd check off things in my day-timer that I had done, I felt that I actually accomplished things every day. I'd always cut the lawn, did things in the garage, even did oil changes and brakes and things on the vehicles. But it took me time....if it took me 2 hours normally, it might take me a whole day or day and a half, but I still felt that I accomplished things. I still pulled our trailer, four days after chemo treatment to Saskatchewan to Enid's grandmother's 90th birthday party. I know everybody was surprised I made it, but I wasn't missing out on a ninety-year-old's party, I'll tell you that! So, I always made an event out of everything for myself. At the time, I felt that the treatment time went by so fast. Because this event would come and I'd make it a big deal and I had to do that for myself, make things an event. And I'd do it again. For me, being productive is important, it really is. I've always got to be doing something, even before this took place. If I had a weekend where I didn't do anything and watched TV all weekend, I'd feel like I'd wasted a weekend. On weekends I get up at seven thirty in the morning, and I drive my wife nuts! (*laugh*) As long as it's sunny outside, I feel there's things that have to be done. I could be outside building a deck, for example - that's my relaxation, doing something. And if things aren't being done, it bothers me. So that's why I make myself lists of things to be done, I'm very much of a list person, I guess.

If I knew a man who had a positive biopsy, I'd suggest he work on attitude; attitude and communication. The one that I'm helping with in Manitoba, I think he's alright with attitude, but he doesn't tell his wife anything. And if you're married, it's a partnership. And you've got to keep your wife informed what's going on, you have to.

Because, like I said before, I think they suffer more than I suffered because they can't do anything for you. Their best way is to prepare meals or try to do something that's going to help, but you've got to let them in. And if they need to cry, you have to let them. Like you just have to be there for them - it's got to be open. Wouldn't it be sad if it didn't work out and you passed away and you didn't let your wife in to help? Now they're left behind with a whole lot of guilt. I think you've got to let them be part of it.

I wouldn't change anything, the experience helped me out. Wherever you go in the Cancer Clinic you see 'depression' signs and they have a phone number. I don't believe in it, and I won't allow myself to get there. It's so easy for people to get depressed, and when they're there it's hard to get out.

Everything that's on TV about breast cancer, every advertisement is all women. I think they should be saying "men and women" because when I tell people today that I've had breast cancer. Even women ask me, "are you sure?" We're all the same. And it does happen. I think they should change the way they do their advertising and make people aware of it, because when I'd look up on the Internet to get information, there wasn't a thing about men. Like the other Oncologist said, our bodies are similar in a lot of ways, but we're different in some ways and we react to things differently. It would be nice to know, "oh yeah that can happen".

We know our bodies, and if it's something, we've gotta get it checked out. But I'm bad, too. I don't like going to the doctor, I really don't. But probably, going saved my life. The doctor I had, a lot of people are surprised I stayed with him. I look at how people react after the fact, like he didn't have to come to the hospital and say "I screwed up". He was very concerned, very concerned and I would go back to him anytime now.

We have a totally different relationship than what we ever had. The Town's an area where people are trying to get off work and I'm not that way. I think he kind of labeled me like that, in the beginning. But he understood very quickly, 'cause even when I injured my knee I was told to go back to work at the end of June. I told him when I was going back to work and it was June 6th, the same as I told him when I was going back to work after my radiation treatments - he had his date, I had mine! (*laugh*). I told him, and everyone in radiation, this is the day I'm going back to work, so fit everything in because this is the date I'm going. Like I said, if I have something in my mind you're not going to change it- that's the day I'm doing it. Like my family doctor says, "you're the only guy I know that tells me what's going to happen!" (*laugh*).

At the hospital, I think the nurses should get more recognition - I thought they were very good. I think doctors need to listen more, because a lot of them are very abrupt - their listening skills are pretty poor. To deal with the patient one-on-one. Sometimes they write you off to something else. I know it's very busy, like the Town is so busy. But when I was at the Cancer Clinic, I didn't feel I was put in any category. When I was there I felt like they were dealing with me and they weren't looking at the clock. They dealt with me and with what I needed; I was their patient and nobody else was a concern. I think other places need to look at how the Cancer Clinic is run. Maybe it's not feasible to run healthcare like that, I don't know. I was told the Cancer Clinic was only concerned about the cancer, not the patient, but I didn't find that at all, not one bit. The Radiation Oncologist, as it turns out we went to school together in Newfoundland. And she'll always do anything to accommodate my schedule - she's excellent. I feel so well in there.

I phoned her a few times at the Cancer Clinic, and she's always phoned me back. I can't say that about other doctors....they just don't phone back.

Lawrence and Grace

Lawrence: Well, I've got these lipomas, they're quite hard. Here's a great one (*indicates large obvious lump at tricep area of right arm)* I've had many of those; they come and go on numerous parts of my body. I ended up with a lump under my left nipple and my GP said "it's a lipoma, that's all it is and don't worry about it". But it sort of pushed my nipple out – I fly a lot and so I'd sit there on an airplane for 12 hours and by the time I'd get there my nipple would be so sore - it would be almost bleeding because of the shirt rubbing against it because it was sticking out. So I went back to the doctor and he said "it's a lipoma, you know. If you want, I'll cut it out." I asked "How do you do that?" and he said " I'll give you a local right here and I'll cut it out". I asked "do we have to do this?" and he said "no, it's just a lipoma, it's a nuisance for you". So I left it for a year, then came back for my annual physical. It was still bothering me and he said "do you want to take it out?"….and then he said "as long as there's no history of cancer in your family". So I went home to Grace and told her about the lump; I don't think she knew about the lump. So I told her what the doctor said and she said "what about your mother?" - my mother has breast cancer - so I realized yeah, we'd better check it out. So we went down and he said, sure, I'll put you down for an ultrasound. And the guy looked at it and said "yeah, it's a lipoma, but it looks a little bit different from the rest, but I'm sure it's a lipoma. However, you'd probably better get it looked at." So I went for a consultation one day and the next thing I knew I was on the table and he was cuttin' it out. Now, before he'd taken a little lipoma from over here (*indicates other area of the trunk*) and it popped out like a little marble. Now this one, he really started to hack away at it. But it still didn't make any sense.

Grace: …you could see the difference…I watched.

Lawrence: …and he was really hacking away at it and he had to shoot more freezing in it a couple of times 'cause it was really starting to hurt……

Grace:….the lipoma had a beginning and an end….

Lawrence….whereas this thing didn't seem to, and the whole time, there's no idea there's cancer. Because there was no information or suspicion that's what it could ever ever be. I had gone to lump specialists, even cancer lump specialists. (*motions to Grace*) Remember that guy across the river? He said "you're a lumpy guy, that's all. Keep an eye on them…that's all you can do. Wait for one to grow big, and then come if you've got some problems with it. But there's no correlation between these and cancer". Then 2 weeks later we get this call from the plastic surgeon. I came in the house and Grace is on the phone - she's white in the face and lobs the phone to me and I'm told, "it's stage 2 invasive breast carcinoma and you're going to be in for chemo and radiation and this is very bad" CLICK. (*indicates telephone being hung up*) So now what??? We're standing around here in the kitchen with my thirteen year old at the time. She's listening to all this and watching the two of us go crazy…and that's how I found out about it. The next day I went to the local GP, but my GP wasn't there - a woman doctor was filling in. I thought 'here's someone who can help me to understand, what does this mean?". We had a copy of the pathology that was faxed to us. All of it was meaningless. Anyway, we take it in to the GP and ask her, "what is this? Is this good or is this bad and what does stage 2 mean?" not knowing anything about it. And she goes "Oooh, my grandmother had that diagnosis." I asked, "where is she?" "She's dead." So we really didn't get anything.

It was the first surgeon I saw who looked at me and said "Ah, this is not going to kill you…" It was the first time anyone had said anything positive about this whole thing. We had been searching like mad on the Internet every day and trying to figure out what was going on. They said that I needed to get in for surgery I was diagnosed August 28th and I was booked for surgery (*motions to Grace*) what, in November? The surgeon said about the delay, "biologically, it's OK but mentally you might struggle." So I figured I could handle it 'till November, but when I got home it turned into instant panic "get this thing off me, get it off now!" So we called the Mayo Clinic and various places and it would cost $50,000. But it didn't make sense to me logically to do it down there, because how do you do all the follow-ups?

Grace:…so we called my girlfriend who is a nurse at the Cancer Clinic…

Lawrence: …yeah, and she set things up. I guess it's who you know at times. Grace started phoning her buddies and the next Friday I'm on the golf course and Grace comes racing out on a golf cart, shouting, "C'mon, we've got a surgeon. If he sees you now before lunch, we can get you in there for Monday!" So we went right to his office. He looked at me and said, "yep, no problem at all" and booked the surgery. And that was September 16th. The worst part of it all for me was not having any knowledge about this and not being able to access any. Anyway, I came out of surgery and the pathology confirmed it all two weeks later. It was almost a month from the original surgery to the time we got the confirmation. Were the margins clear? How many nodes did I have? Two or three out of seventeen? I can't remember it now - funny, it was so important at the time. The nodes were small and the tumor itself was quite small, but there was also vascular invasion. Then, it was time for chemo. It was sort of the same thing again, going

up to the Cancer Clinic and just trying to get an understanding of all this. We spent a lot of time with the folks that do the initiation programs, so we went through that and went for the consultations.

We started chemo November 1st . They say middle-aged men are the worst patients…can't handle the chemo well. I was sick the whole time – I'd have three days of feeling good prior to my next injections, otherwise was sick the whole time. So, I was a wimp through the whole process (*laugh*)! It went well, other than finding out it was the anti-nausea drugs that were making me nauseous more than anything else - I couldn't keep them down. We tried a bunch of different ones, I'd take sleeping pills every night to try and sleep, and it's such a vicious circle. Then of course, I ended up trying Gravol suppositories. You've got to keep them in for 30 minutes and my body rejected them - I would lay on my left side like you're supposed to do and just *hang on*. It was rotten.

I ended up getting sick at Christmas. I had a fever and bad sores in my mouth - I guess they were thrush. I ended up with an infection and in the hospital on Christmas morning and spent a week at the Cancer Clinic in the bubble kind of thing. I came out of that and had my last treatment. They wanted to keep me in the hospital until my last treatment…but I just had to get out. After the last treatment, after the fog lifted, a month after the last treatment - it's been wonderful ever since! I ended up being quite down and ended up on Celexa - my oncologist didn't know if it was the tamoxifen I was on and a side effect of that, or if it was just the whole trauma, so that's where it's been. But it's been a great experience in the end - because every day is wonderful. I mean, it's got me very focused, because in the cancer world you meet a lot of people who are dying. So I've changed my views on life….RADICALLY! It's been….

Grace:…it's been great! (*laugh*)

Lawrence: yeah, it HAS been great…it's the best thing that's ever happened to me in that regard! Because, with watching people die, it's a constant reminder. I was involved with dragon boats and these gals, so many of them were at funerals and stuff. What I got out of that was getting involved with the breast cancer foundation. It's great awareness - that part's great.

And my home life? Well, I'm a CEO of a big company here in town. You travel the world and do lots of big and great things, which were sort of a priority. But now, work's really down….maybe number 10. Really, I don't even know where it sits, because it's completely different. That's not the focus. The focus is that every day needs to be spent properly and to go where your heart takes you, sort of thing. And the kids - I've been driving the kids to school ever since and picking them up. Before, whenever Grace would ask for help, my first reaction would have been "NO". Now it's "No, I'm going to do this – you might never get the chance to do this again". That's what goes through your mind.

I'm eating better, I'm exercising, which I've never done before so, it's positive. But it's always there, nagging - that worry. I had a bilateral mastectomy a few months ago. I'm taking part in a genetics study with the University looking the family history. My father's sister had breast cancer and my mother has breast cancer - both of the women are still alive. I can't remember the name of the test but it'll be two years before we'll know if genetically I have this problem. Logically, they felt I should get the other side done, so it was done and it was clear, no problems. I was going for mammograms and they would look odd. They would say you just have to come back and we'll just see if

they're any bigger. I'd say, "no I just want them all biopsied, I can't live with this". So, every time I'd go they'd just look at me. So it's great to take it off - now that it's gone, I don't have to worry about mammograms - I don't have to worry about the issues relative to that, I just feel a lot better about it.

When it came to telling people about it, we told everybody, but *I* just couldn't tell anybody, just emotionally I couldn't tell anybody 'cause I couldn't handle the reaction on their face. You know, I'd rather Grace tell and I'd come in later - but we told everybody. We had great friends over one night and she'd had breast cancer. She brought over a book and showed me the difference between stage 1 and 2, which probably wasn't a good thing because it showed me Stage 3 and 4! (*laugh*)! And 2 is close to those. But we told everybody.....

Grace: but not everybody in the office. And we didn't tell everybody right away because.....

Lawrence: ....I didn't want the board of directors to know right away, but to tell them properly. I had to be able to tell the board of directors something credible, because if they panicked, it wouldn't be a good thing for them or for the company or for me. We told them when we had some idea of what it was. With kids, well, they were right in the middle of it when that phone call was going on. Vivien was 7 at the time and she picked it up pretty quickly. I remember my other daughter asking "Daddy, are you going to die?" That was the realization, once you get through all of it at the end, it's the kids, you know, all the stuff that you do. Because, I was thinking to myself, "I'm dead, I'm dead" and so what? I mean, it would be inconvenient for me. We have tons of life insurance and financially doing OK...but the kids have the legacy forever. And that's what I focus on, I

have a huge focus on my kids. I don't miss any of that stuff now, it's so incredibly important because they're the ones stuck with it. I've spoken at 4 or 5 different functions, charities and stuff. This coming Monday I'm at a golf tournament where they raise close to 100 grand. I'm a board member now on the breast cancer foundation, so we use the spin of me being a board member and a survivor and male. It seems to get a lot of people's attention, so we've done a bunch of those. My daughter's been coming with me, and she tells her story, and that's more moving than my story. I mean, my story, people get tired of them all. But then Anna stands up and the whole room's a mess because they realize that's the collateral damage - that's the real stuff that's going on. It's not for the research to keep me alive but for the kids to still have a parent.

Grace:…and that's where she is today….

Lawrence: she's on the Canadian youth advisory council. She's in the other City for the day so we've been quite involved. Public speaking scares me absolutely to death, but I think it's such a great thing to be doing, you know? And maybe if I'd seen a male out there, maybe I'd have paid more attention to it. I remember going back to my GP and asking "what the hell's wrong with you? I mean, you are my care provider here and is this not on the radar?" he said, "well it's not on the radar". I read there was 140 men diagnosed in Canada that year, you know, and it should be.

Grace: ….most of them are older…

Lawrence: ….well, I was outside the box. When I went to the Cancer Clinic, there no information about male breast cancer. First was the physio part, which I went to the Cancer Clinic for. Nobody really had a sense of how to deal with me, is what it seemed like. But really, it was a wonderful experience at the Cancer Clinic - I've never been

involved in a more caring environment. People are worried about the health system, but when you're thrown into it, it's fabulous. We were sent to the library, we spent some time in there, looked at some videos. I looked on the Internet and read - there's so much information. There's a few foundations in the US and UK and Australia. The Canadian Cancer Society found me a match for awhile, it was before I got my pathology. Because this fellow was a stage 1 in-situ, he had a mastectomy and nodal dissection. He and I discussed the whole thing and talked about the experience, but once I realized I'd be getting was chemo and everything else, he really couldn't help - they couldn't find a match. There wasn't very much that I felt was relevant to men, at all. Even today. I'm on tamoxifen - tamoxifen's a five year program because women have trouble with cervical cancer. I tell everyone I can't find my cervix so maybe I can be on it longer! When I ask what we're doing after five years of tamoxifen, everyone shakes their heads. That's a question mark on the horizon. With support groups……

Grace: …I'll tell you about the traditional support group for me…that was an interesting thing…

Lawrence: …it was all men, of course, because their spouses were women with breast cancer…

Grace: …it was very depressing. I just couldn't believe that these men couldn't cope…I was blown away…

Lawrence: …it was all about them…about their inability to manage the problem…the home life…

Grace: … and complaining….

Lawrence:…about the physical part of it….

Grace: …yeah, I went twice only. I just couldn't believe *how pathetic they were*. It is just so horrible to say, but I just couldn't believe they couldn't get on and deal with it. It was really pathetic, quite frankly.

Lawrence: Would I have gone to a support group? I don't think so - I think I would have gone to a couple for knowledge, for information, to take what I could get from it. I had enough support between the Cancer Clinic and my family and cancer friends - I had all I needed. I talked to a well-known musician's doctor at the local club. He walked me through the whole chemo experience, 'cause he'd just been on it for six months himself. I'm the kind who'll ask a lot of people a lot of questions of anybody, anywhere just to learn. I don't think a support group would be as effective as doing it by myself….

Grace: But if there had been more men? You haven't found a man…

Lawrence: I'd like to talk to a guy who's been through my experience, you know? I'd like to talk with some guys - if I had a way to talk to guys and see how they're managing, 'cause it's an ongoing process. At Christmas this gal was diagnosed when I was diagnosed, she was stage 1 in-situ with no nodal involvement. So then, boom - it's in her back and bones and all through her, it's terminal. And so she died, I think she died in the spring. So now, every time I get a headache or a backache….I just go into a panic. Because, why is this girl dying with much less of a diagnosis than myself? Why am I the one who is here? Prior to my other mastectomy, we did a bone scan, brain scan, CAT scan, lung X-rays, everything. I came out after all that clean as a whistle…and I thought, "good, I'm good for awhile". So it would be interesting to know how people manage mentally. I'm pretty good at pushing it aside, but every once in awhile….

Grace: …the anniversary, I think, gets to you…

Lawrence: …oh, sure….it's a daily thing. Every day, I say life is grand, but also unconsciously I believe there is cancer in my system that I'm hoping the body can continue to maintain. That whole awareness thing at the Cancer Clinic, when we sat through that whole initiation program - it was about "what is cancer". Statistically it was about 62% of the entire population is going to end up with cancer and 40% is going to be life-threatening showing the wildfire it is. You see yourself as over here, not at the other end of it - that awareness is really good.

When the doctor said "you're going to lose your nipple" I thought I'd better get one sewn on, I mean, I can't go walking around without a nipple. He said, "don't worry about it now, we'll worry about it in a few years.." We went to Hawaii 6 months after the surgery. I was more worried for my daughters - they were a little embarrassed, I think. Vivien said one time "put your shirt on.." and then Anna said "don't do that, that's ridiculous! You should have your shirt off!" And you've seen it, it's quite invasive, quite long and quite big with railway tracks. My new one here, when he went in on this side he cut off all the railway tracks…I'll show you (*lifting T-shirt and indicating to bilateral mastectomy sites*) he cleaned it right up. So, yeah, I'm aware of it. In the guys' shower at the club, once in awhile someone would say "what happened to you?" "It was a shark!" I'd tell them. I guess I'm a little bit conscious of it, and now that both sides are done, people can sort of see. We were out in a boat at Windermere last weekend, I had my shirt off…

Grace: ..you always take your shirt off…

Lawrence: I had my shirt off and we're cruising around like that. Some sun might be good for it. I'm proud of it, in a way, because it's a milestone, no, not a milestone…a

mountain that we climbed. So you know, it's good. The biggest part is that people look at it, and then they're embarrassed that they've looked…it's sort of like seeing a woman breastfeeding…you do a double-take and now you're embarrassed and asking yourself "why did I do that? How stupid am I?" People shy away from you, it's almost like you've got one leg, sometimes. Many people have asked me….remember that one guy after he saw me in the paper….

Grace: now THAT was just disgusting!

Lawrence: (*laugh*) I'm in the survivor's parade and everyone's got pink cowboy hats and vests but they gave me a black vest with a pink ribbon on it and a white hat. But anyway, here I am in the paper in the middle of a sea of pink, you know….one of the guys called me up and said "I can't believe you're doing that crap! Did you cut your balls off or something like that?"

Grace: can you BELIEVE the ignorance???

Lawrence: it's those kinds of things. I've never thought about that, to me it's cancer, breast cancer. It's made it kind of neat, there's a uniqueness to it. Sure, in my spiel I say I guess I'd rather have had testicular cancer and then I could be more of a man for it, but it didn't bother me at all. I didn't feel less masculine at all, less attractive, yeah. It's not the kind of thing you want to show off - I'm not going to strut the beach with my shirt off looking for women (*laugh*). It's a reminder every day….when you get out of the shower. Everything is still numb all through here (*indicates to chest/axilla*) it's a constant reminder. I need to do my exercises, but that's a good thing. They've offered to reconstruct, but now I'd never go and get it done up. That's a man, but a woman, of course, that's a completely different story…it's a physical thing.

If I knew of a man who had a positive biopsy, I'd recommend that he communicate with me on a very regular basis, because there are so many questions and there's not many people capable of answering them. There was nobody that I could talk to, even that guy who had stage 1 in-situ…he just didn't have the same credibility. I talked to a lot of women, I bonded with a lot of women who had the same diagnosis as myself. The most important thing is to find a match, find someone that's close to you who's had that same experience….because the doctors can't do it.

Grace: most men aren't the same as Lawrence, as far as openness….

Lawrence: my sense is that when it happens, if they don't want to be open, they're not going to get any information - it's their call. I searched so hard looking for somebody. The first surgeon I saw said "you're probably not going to die" and I thought "*great*". That really helps when you're asked "are you going to die, Dad?" I remember my surgeon saying, "Ho, you're really got it, don't you?" and you're scared to death of asking "what does that mean?" you know? I asked him if he had other male breast cancer patients. He said "Yeah, I've got one, he's no longer with us". I was just frantically looking for information….am I going to die? Give me some probabilities here - I want to mechanically understand it…even if it's 50/50, at least now you know and you're not running around worrying about it. So, I'd recommend that somebody get connected, whether it's a man or woman with someone with a similar diagnosis.

Grace: I think that man in Saskatchewan really disappointed you….the one that had not needed to have a mastectomy….

Lawrence: So if I could recommend something, I'd tell people to hang out more at the Cancer Clinic….I should have been there earlier.

Grace: you didn't ever want to go there....you hate that place...

Lawrence: ...well, that was after the chemo. Before the chemo, we should have gone to psychosocial services, but nobody could tell me what I was up against...they just said "You'll feel rotten for a couple days and you'll be fine. Chemo today is not a problem..." and on and on it goes. Where do you go and get that information? That's the key to it. And not knowing, was just the absolute worst thing. If you know you're going to die, well then that's probably OK too because you know it. Written information would have to be pretty specific - much of the written information is so general that it's meaningless, I found. I learned what breast cancer was and all those things, but couldn't find what this meant for me.

We just did a video, with me in the background of it. The video is all about everything else, with all the other effects discussed...the spouses, the kids and men getting it. That's what I do with my spiels; you hear a roar around the room when I get up and tell them that it's me...it's ME with the breast cancer!

If I could go back in time, I would have looked at every lump a little more seriously. I was worried about it, and the professional community said "don't worry about it". When I went to the cancer lump place, they told me not to worry about it....

Grace: ....and you had complained about it 7 years previously. He always talked about it rubbing. When you went to Japan with your mom, that was the first recognition....

Lawrence: ..when I went to the lump guy, he said "you have hundreds of them, we can't take them all out". But when it came to that lump - get a needle biopsy, at least it's a start, talk about them. My GP, when he said it wasn't on the radar, I thought "there's something wrong here". When I was in Europe, long-haired and backpacking I had a

lump on my back and went to see a German doctor. He said "no no, this is a lipoma and there's no relationship to cancer" and maybe that's true, but a lump's a lump and you've got to think of it as a potential problem for you - get it looked at. And male breast cancer needs to be on the doctors' list. No matter how low the risk is, even half a percent....you still have to pay attention to it. Percentage-wise men are dying more because they don't want to go to the doctor, they don't want to admit they've got this issue. Also, no-one's looking for it...so when they find it, it's too late. I should not have relied as much on the system as I did. I was asking all the questions, and not getting the answers. When he first said we could cut it out, I was worried how much it would hurt because he wasn't going to put me out, he was going to put me up on the table, give me a local and cut it, but everyone was telling me it was nothing.

Something that bothers me is how the system has evolved. At the Cancer Clinic I get instant recognition and attention, and they're committed to however long it takes to answer all my questions. But if I go to my GP, he has me slotted in for 15 minutes and there is no time. I go in there with 3 or 4 things and I'm driving the guy crazy. He asks, "so what's your biggest problem" and I don't know, I want to talk about it. People need a place to go and get information. The people at the Cancer Clinic can give me information, but they can't help with the feeling side. If I could talk to some guys...that would complete it for me, you know.

Apparently, there's two similar genetic defects, one that can cause lipomas and the other breast cancer. But what about the family....what would you suggest, Grace? The girls didn't like going to the psychologist at all. I had thought it would be a great thing for them to do, to go and spend time....

Grace:… it's like anything….you need a doctor to fit…

Lawrence: ….but they seemed more worried about me…

Grace: …but you're the one who's sick…

Lawrence: …..at the end of the day, you guys had the worst experience. I had the physical problem - I felt pretty useless….

Grace: …..you were supposed to be…

Lawrence: …you're used to the company where you're the king all the time…now I'm walking around in my pyjamas moping around, trying to figure it if I can help Grace get more efficient around here….(*laugh*)…I'd ask, "why'd you do it that way?"

Grace:…*(laughs)* When you've got somebody at home sick and you're not used to it…I'd go about my day and do what I need to do, right? It was 2 o'clock in the afternoon and he was sitting there. I went to walk out the door to eat lunch and he asks me where I'm going. "I'm going to have lunch!" and he said "it's 2 o'clock in the afternoon!"

Lawrence:…you could see Grace was looking for a way to get me out of the house! Retirement scares her even more than anything else, now! (*laugh*).

Grace: We were all so extremely blessed that he didn't have to worry about his job.

Lawrence: I basically got a 4 month leave from work. The board said, just do what you have to do, it will be a good test of your leadership…just go. I just can't imagine having to worry. Being the primary breadwinner, then not having a paycheque coming in. I felt useless enough as it was. I always said to the kids "Dad can do anything", you know? But I couldn't fix this. Suddenly, you're in need of care and attention and support. It's a hard place for a man to go…to lay back and say, I do need this.

Theodore's Story

I think it was April of 2003, I had an umbilical hernia and it ripped. I went to my doctor and he said he would organize surgery for it. So he was setting up the surgery and I was waiting until he got off the phone. Before I left I asked him to take a look at a lump I'd had on my chest. It had hurt, then stopped hurting and started itching. I wasn't sure how long it had been there, but noticed it when it started hurting a couple of weeks ago. Then it stopped itching, then just nothing. Right away he wrote out an order for me to go to the Breast Clinic on the south side. I went over there, they gave me a mammogram, then the doctor came in and examined me. She said she was so busy, she wanted to do a biopsy but just couldn't work me in, would I mind coming back later. I said sure, and I came back here and had my hernia operation. Then I got a call from the breast clinic to go back and do the biopsy. My doctor called me in after supper - you know when they call you in after supper, it's not to tell you good news. I went over there and he told me the test was positive, that I had cancer. He left and let me sit in the examination room. I sat there for awhile and kind of pondered this, then got up and came home. He started the wheels in motion for a radical mastectomy, a modified radical mastectomy. Everything was going fine - the date was picked and so on, then I had to go over and meet the anesthesiologist. So I met the anesthesiologist - she examined me and said no way she was putting me under. So, that cancelled everything. They sent me to another hospital, and I went through all the stuff there. We did the after-operation care, the lymph nodes and physiotherapy. I went through counseling with another nurse to prepare you for this with some other ladies in there. Then came the examination by the anesthesiologist. This one, "no way" he would put this man under without a hospital with a complete ICU. So,

that cancelled everything there. Then they sent me to see this doctor in the City. He examined me, listened to my lungs and that sort of thing then said he was going to send you to the cancer clinic to try and shrink the tumor. He didn't want to operate on me, either.

So they sent me over to the cancer clinic. They treated me quite well over there. They put me on medication the same day I went over there and I've been taking it ever since. It shrunk the tumor until it was gone – there's nothing left. I was there a couple of weeks ago, I'm on a six-month recall while I'm taking the medication. One of the residents over there said that if they put me under, I wouldn't wake up - my lungs are shot. I've got COPD real bad, I'm on all this stuff *(indicates pill bottles)*, I'm on oxygen at night. The hernia operation was different; they put me to sleep for that but they said it's different. When they do the mastectomy they gotta make you like you're dead, 'cause you can't move a muscle. They're working around these arteries and stuff, so it's a different type of thing. With the hernia, they put me to sleep and away they went.

When I was diagnosed I told my wife, then family members, then close friends and that. When I first found out, I told everybody I had chest cancer…that I had cancer in my chest. Finally I came clean and said I had breast cancer. Like everybody else, I thought it's a woman's disease, it was nothing I ever had to be worried about. Women get breast cancer and men don't - then to have that dropped on you. It scared the hell out of everybody.

I worried about it coming back, especially when they were talking about it metastasizing and they were checking me out with all these different tests. Then I got an enlarged thyroid. They did a biopsy on my thyroid, and I didn't like that, because I feel

that's how that stuff metastasizes. They start poking around in there, and there it goes, eh? Anything that starts with cancer scares the hell out of you, I don't care who you are or how old you are. I was really bothered by it.

When I went into the cancer clinic they were (*starts to cry*)…they have a very good support group over there ….excuse me….anyway, they meet when you come in and they take pretty good care of you….but I didn't want to discuss this, you see…that they did, these women who had the operation and all this, they're very supportive, but I didn't want to talk to them ……(*still crying*)…….....and I didn't……..I just wanted to be left alone……..huddled in my corner……they wanted to reassure you……but it's kind of a personal thing, eh…….especially that kind of cancer…..(A) I hate people making a fuss over me ….(B) I like being left to my own devices, you know……it's a wonderful place, that clinic…..I can't say enough about it….just a great place. And other than that, other than my oncologist, I never talked about it to anybody. You go through that routine, you go to the lab, you go in there with the nurse, and then the resident comes in, my oncologist comes in, but there are no counselors. I never had a hard time handling the news, never had a hard time handling the disease. It was extremely worrisome, but I never flipped out or anything.

You know, it's kind of a "why me" kind of thing. In the last 10 or 12 years I've had a lot of problems. Before that I wasn't sick at all; I spent 12 years in the Army, 25 years at the phone company and was never sickly, not at all. Then when I retired, all these things started happening. You kind of look up and say 'why me, what did I do?". I say I'm cured of cancer, but they say there's no cure. Nobody's ever said remission,

nobody's ever said anything. My last visit to my oncologist was very brief. She came in, checked me over and said I'll see you in six months and she was gone, in a matter of minutes. She doesn't seem to be overly concerned with my case, therefore I'm not concerned with my case. It's gone, as far as I'm concerned. I don't like taking up too much of her time, she's a busy person.

I think I'm fairly well adjusted with the situation now. It's not something that keeps me up at night, not something I worry about everyday. It IS something I worry about every time I have to go for my visit. I start wondering what's happening and this type of thing. As long as I take my pill, nothing happens. It's a funny disease in that I had no pain, I wasn't sick. There's nothing there, but they say I'm sick. That's the big thing - they say I have cancer, but show me.

My wife was very concerned and my kids were very concerned…..my daughter cried and the boys wanted to come home. I told them it's not that type of thing, it's nothing dire, no big deal, just wait and see. My wife is a pretty tough cookie (*laughs*). She would never let me go alone to the Cancer Clinic or any of my appointments - she was right behind me and in there with me.

That's why one guy peed her off something terrible. The doctor I was supposed to see about my thyroid was on holidays, so they got me in to another doctor from the University. I went and seen her and she did a whole do-up on me and she decided she didn't need the biopsy - she didn't want to go in there and monkey around. So when the first guy came back from his holidays, they called me in and said I'd better keep the appointment with him. So we were in the office and there was nothing for him to do, cause this lady had done it all. So he says "we'd better do a biopsy". Why? "Well we

have to", he says. So we went to go into another room and my wife says "no, I don't have to see that" and he says to her "well, aren't you supportive (*with sarcasm*)". Well she damned near got up and floored him, because she is so supportive. And it was a good thing she wasn't there because they went in with this needle. The needle wasn't big enough and it was too short....so they went in with this other needle - they did it twice. I thought "holy crap, here I didn't want it done once...."

I haven't noticed any side effects from the treatment. They said my hair would get thinner but I got skinny hair, anyway. I found no side effects at all. I've still got a lot of the information they gave me. One of the things that bothers me is constipation and they said these pills might make it worse. They gave a bunch of stuff and I bought it just in case. I was treated very well over there.

(*wife arrives*)

Irene: We were treated very well. The reading material was helpful.

Theodore: Those support ladies were there and sat with us....we were treated very well. If there was another man to talk to, well, that's kind of hard for me to put a finger on... because mine went away. So somebody that still has it or had the mastectomy or something like that, he would have a much different opinion than I would, you know.... mine was just like I had a cold, and now I don't....

Irene: Yeah, but it was terrifying at first 'cause they were going to do the mastectomy right away....

Theodore: There's really not enough information out there, nothing about this as a disease in the male population. Like it started off with my doctor; he says "in 30 years of medicine it's the second case I'd ever heard of. You hear statistics like there's 400 cases

diagnosed every year, but that's not really out in the forefront, eh? Male breast cancer is kind of a *(indicates secretiveness)*"…well, we don't talk about that, you know…." whereas women's breast cancer is a runaway thing. They need the money, they need the funding, so it's front and center - everyone knows about women's breast cancer because they need the funds to fight it. But men's breast cancer…..*(gestures off in the distance)* "well you go over in that closet over there….." But then, if male and female breast cancer is the same, what they're doing for the women is beneficial for the men, too. I think we need perception and public awareness that male breast cancer is a reality. For the first while, I called it chest cancer… it felt kind of weird to have breast cancer.

Irene: One lady at the Cancer Clinic said a lot of men have it, but they're not diagnosed because they feel it's a stigma. By the time they realize it, there's something really wrong. He was kind of reluctant to go the doctor when he first found the lump, and the lump got bigger before you went to the doctor …..

Theodore:….no, I went to the doctor for something else….

Irene: ….and you just mentioned it….

Theodore: You know, they say catching this stuff early is beneficial, but then we go to this guy here, then we go to the breast center, then we wait and go for a biopsy, then we wait and go back to see this guy, then we wait through all those different steps I told you about, then we finally end up at the Cross. By this time it was the end of June. They say you've gotta catch this stuff early and all this time was going by between appointments. And that was worrisome, that nobody was *doing anything*. So when we got to my Oncologist, finally we said "when is somebody going to do something???" and she said,

"I'll be doing something right away! Before you leave today, I'll do something" and she did. She gave us the pills and they seem to have worked.

Irene: The pills you're taking…they're hormones, eh? We don't tell people that….we just say it's a pill form of chemo…..

Theodore: They block estrogen. I didn't even KNOW I had estrogen, for God's sake!!! Anyway, it blocks estrogen and that's what killed the cancer. You don't tell everybody that you're taking a pill to block your estrogen! (*laugh*) That's the type of society we are….we're a society of cubicles….."what, you're a man with breast cancer?? You go to this cubicle over here…." you know?

If one of my friends told me he found a lump, I'd tell him to get to the doctor right now. Don't even wait….I tell you. That's so important, even if it's nothing. It's better to have them tell you it's nothing than you to be harboring something. Mine wasn't annoying or anything, I just thought "gee, that hurts" then it stopped, then started itching and then the lump became quite pronounced. It started at 12 o'clock and then it moved down to 9 o'clock and got hard like a little pea. You could feel it in there, it was as hard as a rock. Then by Christmas, it was gone. When we went there for our December checkup I was sitting there looking for it so I could show the Oncologist where it is, and there was nothing there.

Irene: They would send him for all these tests; they would find a spot on his adrenal gland, they would find a spot on his thyroid. We were terrified for months, because then we'd have to wait to see a specialist to have a test done. They said it could metastasize - that was the scariest part, that it was spreading. They kept stalling us, and that was the

worrying part. Waiting for all these tests to get done - we had to wait for 3 weeks to see the thyroid specialist.

Theodore: Another thing was my lung problems. I went to see a lung specialist, and through all of his investigations he sent me for a PET scan, back at the Cancer Clinic. I was really glad to get that. I had the scan and passed it beautifully. That took a lot of weight off my mind too, because being a longtime smoker and now that I've had a touch of cancer, then what's the next thing? But I don't think I look at life differently. Although, I've always thought I was going to live a long time. My parents were both long-lived and I felt I should live that long, but now I've started wondering, you know? Once you start getting things like this, I wonder what that means - what is changing, what is happening?

Irene: Maybe he just worries more. If little things happen to him, it scares both of us, actually. But it really worries him. He gets these marks and things on his hands and he worries more about things that are changing on his body, more than he did before.

Theodore: And I'm a diabetic, not a very strong diabetic, I think. I get these phantom pains in my feet and I think "Ohhh". You hear stories that one thing about diabetes is you lose your feet. I agonize about that, but that's not cancer, that's the diabetes thing.

Irene: That's the thing that I notice that's different. He worries more about the changes in his body than before. He's more inclined to see a doctor now, whereas before I couldn't drag him to the doctor. But we've got such good medical care. We have a beautiful facility, with a surgeon and a pediatrician. That was another reason we moved here, we're getting older and we wanted to be near good medical care. When he told me he had cancer I was so scared, and I cried. He wouldn't tell me at the restaurant, but I held it

together pretty good. Every time we'd drive in to town for another test, I'd cry all the way in there and all the way back. He's just never been sick, he's just been really strong and everything. This was a total reversal, because he's always kind of looked after me. He's come through it so good. I always said we were soul-mates. His niece was also diagnosed with cancer, and she just died recently - it was really awful. That was going through our heads, too.

Theodore: She was just 34 years old, a beautiful girl.

Irene: I think it touches everybody - just the word cancer scares everybody……

Theodore: I'm really not classic - I dodged a bullet…I hope it's gone, gone for good…I wonder, if you organized a run for men's breast cancer, how many people you'd get out. For health professionals, I don't think there's anything that health professionals have to work on. They're very well set up to handle this. With this men's breast cancer, there should be no worries by anybody that you're not going to get the proper treatment or timely treatment. As soon as we walked in there and the wheels were in motion.

Attitudes….it's hard to say about attitudes. When it first happened I was scared, worried. People I'd leave behind….there's a hundred different things to worry about when you're diagnosed with cancer. Cancer? Cancer? You can't believe it…..you know? And once that sinks in, well…..it's scary. And I have nothing but sympathy for those guys who've got it.

Irene: And not having to go through the chemo or radiation or anything like that. A friend of mine just passed away from another cancer. I went with her through chemo treatments; I thought "I can't go through this" with him, if he had to go. I was just about physically ill going in the chemo room, I was so scared going in there. When I went with her, I'd

just sit there and shake. She got to know everybody in there, and of course she was there 2 or 3 times a week and she'd say "these are all people with the same thing I have and we're just doing the best we can…" but it really bothered me. I saw what it was doing to her, too….

Theodore: My attitude never did get really bad, even when we were going through the exercise with the mastectomy. I never got really down, I was worried…..

Irene: It never was a vanity thing with you…..

Theodore: I had thoughts about that, but nothing lingered. I got assured right up front that it's a man's disease, too, nobody said "hey, you're the first!" I was told there was 400 cases in Canada each year, I wasn't alone. You know, you kind of worry about "femmy" stuff…..it kind of crossed my mind, but nothing I dwelt on. Since I was diagnosed, no-one had asked the question about being a guy with breast cancer, you know. But I'm sure getting used to being the only guy in a roomful of women!

Brian's Story

I was in to see the doctor and a surgeon a couple of years earlier when I had a lump. Basically, the surgeon said, "get out of my office, sometimes it's better to leave your knife in your pocket", after I hadn't been in his office more than 30 seconds. He basically kicked me out. Two years later I could feel the flesh around the bump was getting kind of firm and I knew something was going on. I suspected that this was what it might have been all along. So, 2 years later he says, "Jeez, maybe we should do something about it." So he makes an appointment for a biopsy, takes some of the tumor out and calls me a week later. Well, the secretary called, and I'm thinkin'…. "this is not what I want to hear", but I wasn't surprised. So I went in there, pretty well knowing what it was. And he told me. It kind of hit home, but I was sort of ready for it, because I'd sort of suspected I had it for awhile. I guess maybe I should have went in sooner, maybe could have rescued me sooner. If I had been a woman, they would have done something, but when you're 0.5% or whatever it is of all cases, it's pretty rare that you're going to come across one in a small town.

I remember in grade 3 or so I had a piercing pain in the area where the tumor was. I was eating lunch and just like someone jabbed me with a hammer or a knife….right there (*indicates chest)* and it lasted for about 10 seconds, then it went away. Right where the tumor was. And when I got the lump there, that was in my mind. I asked the family doctor how long ago he thought this started. He said "well, maybe about 5 – 10 years ago". I said, "well, how about 35 years ago?" and I told him the story – he was doubtful. But I still think it was, because where would the pain come from, then, and why was it in that exact same area? With working in the oilfield, sometimes there's lots of

chemicals….. toluenes, benzenes. Maybe that was part of it. I got genetically tested, and it was 3 and ½ years before I got my results. I just got them this spring, but I was negative on both traits. I guess that doesn't mean anything, really.

After the surgery they told me it was cancerous and they had to take out more, because the edges of the biopsy were still positive. 'We have to do the full deal with the lymph nodes and everything'. And then that came back, and I think there was 1 out of 10 lymph nodes that was positive, so then he said "you need radiation and chemotherapy". I was devastated. I was just separated then, and that was just such a blow to me that everything else didn't matter that much. I tried to deal with both issues, with my treatment. I had tough times with the chemo, but I got through it. Radiation was kind of like a walk in the park after that (*laugh*). I thought "this is alright".

When it came to information, they told me where the library was, and I checked out a few books. I got a couple of pamphlets, read them and got the gist of the whole thing. And then I didn't look at it again, because I thought I'd seen enough. I just read a bit and found out what stage I was at, what the odds were, the side effects of chemo and radiation. I basically closed the book then and just said "I'm going to beat this". They offered quite a bit of help, but I didn't have many questions. They told me male breast cancer was rather rare, but as far as they know it's similar to the female version.

By the time I was into radiation and went to the other Cancer Center, it was a little different - I just went in there for treatment. I was assigned to the guy who set my radiation up. The Oncologist did the planning and a junior guy followed me until he was ready to graduate me, or discharge me from follow-up. I told him "I'm not ready to graduate yet, I didn't pass grade 9", and he tells me "well, I think you're done in

December". I said "no, I started my chemo in December 2001 and finished my radiation in July, so I'm 6 months away". So he looked at my chart and he said "I guess you graduate next time". I guess he's pretty good, but I was surprised at how basic the examinations were - like 30 seconds. He feels under your arms for any lymph node enlargement I think, and feels across the breasts and the neck and asks if you have any questions. Basically, that's it. I thought "gee, they should be able to monitor it better than that, I could do that at home". And that's what he tells me, that I should do it at home. And I said "well, I don't know anything about it". So, when he does the same thing, I think "holy shit, nobody really cares…." But, maybe there's nothing else they can really do. They tried to fire me after the 3rd year. I was pretty sure my first Oncologist told me they would be monitoring for 5 years, and so I told the Cancer Center people that I wanted to keep going back. But I felt was a pain on the system, that I should "get out, we have other patients"….that's kind of the way I felt. But I didn't ask for a new Oncologist.

One thing that I really wanted to do was one of those scans - I think you can do it in Vancouver. It uses a metabolism thing to show the scanner where there's a high metabolism rate to find the cancer. But he encouraged me not to do that. I think the reason why is that it's gonna show something and then I'm gonna be worried about it and I'll be going to him all the time and they're already busy. That's what my take on it was - that they didn't need me in there because there's enough real cases to try and diagnose. So, I was a little ticked off about that and then I thought "well, maybe I saved a couple grand!" (*laugh*). I asked him, "well if I have cancer, don't I want to know it?". And he said, "you'll find out soon enough".

During the time I was going through the separation and diagnosis, I guess I relied on my parents more than anything. I never was really that close with them, but during those times, they actually did what they could, which wasn't much. They talked and listened, I guess. I didn't tell many people about the diagnosis, basically my family and a couple of friends. Over time, it becomes apparent - when you're taking chemo and stuff. I told some of the people I work with and I imagine they told other people I work with, because I didn't tell everybody. I usually would tell people what kind of cancer I had…..I'd say "believe it or not" (*laugh*) . It's almost embarrassing, but then on the other hand, I'm embarrassed because I'm all cut up and don't look the same. But I'm glad I'm not a woman with that situation - that must be devastating. So, I guess I'm glad I'm not a woman! (*laugh*). I don't know, I just don't like being all cut up and scarred and that.

Support groups wouldn't have interested me. Maybe once, but I'm not into all that group-y stuff. I just kind of look after myself and deal with it. But talking with other men who had similar experiences might have been helpful.

I think one of the big things, maybe other people feel differently, but being separated and divorced a little later made me feel very inferior. I'm not physically looking the same anymore. If I was still with my wife and that, it wouldn't have been as big a deal, I think. But now you're out and about and maybe you want another relationship or whatever, and you feel self-conscious about it all the time. I found that the worst part, actually. I don't go without a shirt. I'm down to a muscle shirt - my oncologist told me not to ever expose anything to the sun. I thought he must be getting a little carried away, cause he said "you've got enough radiation now for the rest of your life, you shouldn't have any more." Then I talked to some women who had breast cancer and

radiation. They go around with their bikini tops or whatever and say they just don't get burnt to the raw. This year I tried a muscle shirt and got a little bit of a tan instead of being all white. My oncologist really scared me. I think that just because he's an oncologist, he says you shouldn't have any sun once you've had radiation - it's a big taboo. But I didn't go out and get crazy, I just would get an hour or so of sun on the weekend. So, I never go without a shirt, except when I'm by myself.

I think my friends felt sorry for me. Nobody ever said anything, they just listened. The gal I work with, I just told her last week. We started working together in December, I guess it was, and the opportunity was just right and I told her. Then I met a guy who was buying my car and he was going through chemo, so I told him, too - this was just last week, too. It's a small world, sometimes because I met him at the Cancer Center last week when I went in for my checkup – he was going in for chemo.

The scar's still a little bit tender, but what bothers me is the way it looks. They cut everything out, it's not very masculine looking. Looking back, if I had known more, I might have negotiated for a different type of surgery, not taking so much tissue. But they just ripped it out with the second surgery. I thought "oh, shit.."

I've thought about reconstruction in the last few months, wondering if I could get it fixed up to look more normal. But you know, it's vain. "Do I deserve that? Is this the way I am now? Do I have to live with it?" When I asked my oncologist if I could exercise after radiation, he said, "well, you weren't Charles Atlas before, so you're not going to be in the future, either." I decided to exercise anyway, but to take it easy.

Looking back, it was a double-whammy for me. First of all, I blame myself too much for my separation - I don't know why. After my separation I stayed with my

brother on the farm. He'd say "come and help me work on the equipment" but I felt I couldn't even turn a ratchet - I was useless, like a vegetable almost. So when I got this cancer thing, it didn't change things a whole lot. I blame myself so much, I thought I'd better really think about how I'm living my life and don't screw up again. Later, I found out other things that happened that were out of my control that aided in the separation, or maybe was the major cause, and I thought, "OK, it wasn't really all my fault…"

Still, with cancer life is really fragile, whether I look at relationships or cancer or whatever. I'm trying to make the best out of every minute now instead of assuming I'm going to be here next year or next 5 years or 10 years. For awhile there I was living for the next hour, but now I live for the next year - it's different now (*laugh*). So that part is all good, I guess.

Now I try to go out and meet as many people as possible. I don't really have too many close friends, I'm kind of a standoffish kind of guy. I just protect myself; I don't make myself vulnerable like some people who are bubbly and stuff - I make sure I don't get in those situations! (*laugh*). I probably have more friends than before but, probably because I'm single now. Before, I didn't feel that need. I was busy, too - I was working full-time both in the oil industry and on the farm, so I had no time for friends. I've started traveling, too – I had never traveled before. I went to the States a couple of times, and now I'm going more overseas - I've been to Australia, Dominican, Mexico and that's all good.

If I could go back in time, I'd have gotten a second opinion, but I trusted my doctor…he knew best. But yeah, that's one big thing. The other thing is about life – I'd maybe try to be little bit lighter and more open to things, 'cause you never know what

might be coming around the corner for you. For another man diagnosed with breast cancer, I'd give encouragement, I'd tell him that he'd get through it. Not to worry, if he had any questions, to come and talk to me. I'd call him often, because he might not want to call me because it would be like complaining, so I'd call him. Just to see how he's doing and to listen to him. I'd let him ask or encourage him to ask questions, just for support – to get it off his chest. That's what I'd do.

Overall, I think the doctors and nurses were pretty good, I think. My oncologist answered a couple of my questions rather shortly, but it was nothing too serious, you know? Like about exercising and getting a PET scan. It's been pretty good, overall. I think most of the written literature applies and I'm not much for reading literature anyway, so it doesn't bother me.

With respect to chemotherapy, they gave me some stuff to read, but I don't know if you can ever be prepared enough. I wasn't looking forward to it….*at all*. The first time I took it, I got sick and I thought "this is what it's all about" and the next time when I got sick it was even worse. I don't know if you can be more prepared or not; I knew it wasn't going to be good, and it *wasn't* good. It was my second or third treatment - I was living by myself then, 'cause I'd moved out of my brothers' and got my own place by then - my kid was in town that weekend. I called him, 'cause I didn't even want to drive to the hospital I was vomiting so much. I actually stayed there all night. They got my stomach settled a bit, but basically, I got through it myself. I called the cancer clinic after the first treatment; they gave some advice on what to expect or whatever. It's been five years, now. I can't remember all the details, and you don't want to remember that stuff. At the time I knew all the drugs I was taking, all the different types of chemo but, a few months

later I couldn't remember it anymore. I just didn't want to think about it - there was no room in my brain for that nonsense! It was different….I don't know if it was easier or tougher because of my separation, but it was not good, though.

I didn't take many days off work. I went to work a lot of days, but basically I got nothing done. It's not like I didn't have energy, it wasn't that I don't think - I had other things on my mind. My boss was in the city here and I was still living in Town. I told him I'm at work, but I'm only getting like 10% use out of my time. I said I just can't deal with this stuff right now, but as far as being manly the biggest thing that bothered me was just getting all cut up and not looking like one anymore. It wasn't any of the other things like being a provider - my kids were gone already, that wasn't an issue. My kids never said too much. My youngest is in med school and he never ever talked to me about it. The older one, he felt kind of bad about the whole separation thing at first because he knew about it before I did, apparently. He just encouraged me the odd time through the whole thing, didn't say much but just was kind of there, you know?

My ex - it was kind of funny - she was the director of nursing at the Town hospital, when she saw my chart and called me. She saw the order, that I was going in for this mastectomy, 'cause I never told her. And she said, "have you talked to the kids?" and I said, "no". So she said, "maybe we should talk to them," I said, "maybe you can talk to them, too, you know more about it than I do…." I don't know if she ever talked to them or not. When I talked to them, they didn't really say anything, just kind of "Oh," And that's probably the way I would have been at that age, exactly. Just, "oh". I would have thought lots, but I couldn't express myself.

She helped me one day, I was rather surprised. When I went in for the operation, when I woke up she was there, and her mom and dad were there, and her brother and sister were there, they were all there. None of my family was there, except for my oldest kid. The other one was at university at the time. The next morning she came into my room and talked a bit, then walked down the hall with me. Kind of weird, because I wasn't sure if she was living at home or had moved in with this other guy already, but it was weird. With her walking down the hall with me, with the other nurses around and we were separated. I thought at the time, "this must be weird for her too", but I guess it didn't matter. She kind of supported me just in being there, whatever it meant. It was kind of good of her, but it didn't really mean a lot to me. She booted me out in April and it was July when I was diagnosed and October when I got my first surgery, then it was only a week later when I got the major one. But I always somehow thought we would get back together, so it was kind of hard.

I knew a lot of this would come up in this discussion, because it was so interrelated with everything. My feelings are all kind of misaligned because of that other thing - if it was just the cancer I was dealing with it would have been quite different than my situation. I blend them all together and talk about both of them together.

I haven't really talked to anyone about these thoughts, maybe a little bit with a friend of mine I met after I came to this City. I'm pretty good friends with her. I tell her a few things, but she doesn't respond, so I don't tell her too much. I think she listens, but she doesn't respond at all. I've talked a little bit to my parents, my brothers, my sister-in-laws, but not a lot....

With this project, I just thought, "why not?" If it helps to teach your patients, with the research, with your project it's no pain for me to go through, so why not? Plus, maybe it's good, I don't know. Maybe it's good for me to talk about this. I never even thought about that part of it before. I haven't talked to anybody like this. It sure opens up your eyes, how fragile things are.

The biggest thing for me is just being all scarred up and feeling not manly and insecure or whatever. Here's one example: when I go to the gym I always try to throw a towel over, I try to hide it. When I'm in the shower, I turn the other way – I try to not let anyone see without being too obvious. At the gym, guys are all macho, and here I don't even have a proper chest (*laugh*). I thought "what am I going to say if someone sees it and says something". Maybe I could say, "that's what cancer does…"

Cancer never made me cry but my separation did - it was less significant than my separation. Being single again and maybe wanting to be with someone again, it's just so hard. And I blame the cancer thing, because it's here but maybe that's holding me back from building a relationship. I'm thinking it's what gets in the way, but maybe it's all up here (*points to head*). Other people might have things to worry about too, but they might not let that get in the way of relationships. And I'm letting it get in the way! (*laugh*). It's that hard shell, I think! And I try to avoid situations, like beaches and stuff like that, where you're supposed to have your shirt off to be manly. Well, I did do beaches in Australia, but I had a muscle shirt on. There were a few others out there with shirts on, so I tried to hang around those ones! (*laugh*).

I probably wouldn't have bought this big house close to downtown and spent the big money, if I hadn't gone through that. I had gotten everything in order, liquidated

everything and wasn't going to invest in anything. I waited 2 years after I came here; I lived in a basement suite, then an apartment. Finally I thought "No, this is going to work", I'm going to start investing in living and stuff like that, it's been good. I'm going to graduate, too!(*laugh*)

Chapter 5 - Analysis

Narratives are an extremely rich source of experiences, thoughts and meanings. There is a great diversity of narrative approaches a researcher may adopt and abundant methods of analysis. Sandelowski (1995b) suggests that even during data preparation or transcription, the researcher will begin to develop a sense of the interview and its essential features. She advises that within open-ended and minimally structured interviews, there are only a few key storylines. To approach the data systematically, Sandelowski suggests an approach in which the researcher identifies the topic area or storyline being discussed (p. 374). She provides an example from her research with parents telling the stories of their babies' illness, describing two general storylines: what happened when they found out and what they did afterwards. From these storylines, the researcher can further explore with the teller what events contributed to these experiences. By employing a creative qualitative approach (Sandelowski, 1995b), new knowledge and understandings can be created that are faithful to the data or stories.

Sandelowski (1994) suggests that the tellers of the illness story plot their lives as a romance, comedy or tragedy where as protagonists, they struggle to overcome obstacles along the way. Tellers employ culturally familiar narrative forms to tell stories that provide a sense of connection between life events. Frank (1995) concurs, stating that as people compose their stories, they adopt and combine socially available narrative types. He proposes three general narrative types or forms of the illness story: restitution, chaos and quest. At the same time, Frank (1995) cautions that applying types or categories to stories is not to make them 'fit' some predetermined idea; rather that the attention to storylines or types may assist the listener. He states:

> Listening is difficult because illness stories mix and weave different narrative threads. The rationale for proposing some general types of narratives is to sort out those threads. (p. 76)

In modern society the restitution narrative is valued, where the individual was healthy, became ill, but through the power of diagnostics and technology will resume health and normal life again. Chaos narratives often remain untold, as the lived illness experience is so devastating and overwhelming it is impossible to articulate. The third form described is the quest narrative, within which the teller describes the lessons learned while journeying through and facing challenges brought about by illness. While the forms may vary and mix within the same story, Frank (1995) proposes the story may be described by the form that dominates at the point of telling. By virtue of a good fit with the stories as told, I have therefore adopted Frank's narrative forms to discuss the experiences of the participants.

Restitution stories

Several of the participants identified their experience with breast cancer as a brief medical event without major long-term ramifications. The problem was identified, recommendations made, the operation performed and normal life resumed with little, if any consequences. Mitch describes his perspectives on cancer:

> Cancer is cancer, what the hell? Like I say, I'm an old technician and so, if you got a broken piece, you take the broken piece out and replace it with a good piece.

Later, Mitch adds another statement:

> After the surgery and finding out that it was all gone, the rest of it was just like any other surgery, like having a tooth pulled, you know? Leave it alone, stop the bleeding and it will heal up.

At the end of his story, Hector summarizes his thoughts on his breast cancer experience:

> There's no advice that I can give really, because some men are quite reluctant about it and I'm not. Like I said, it was like having my tonsils out - if it's bad, take it out. I think it would bother me a lot more like if I had to amputate a leg or something, you know?

Garth felt that as his cancer was dealt with so promptly, he experienced little if any long term concerns:

> In my case it was so fast and it was over, the breast was gone. Physically, I was feeling great within about 2 days. I think that if it had lasted longer, if I had worried or fretted about it for a longer period of time, waiting for an operation and all that - it would have made a heck of a difference in how I would have needed to deal with it.

In these restitution stories, these men tell of the identification of a problem, the measures taken to rectify the situation, then life going on without significant ramifications. They assumed a mechanistic view of their body and the experience, with a 'fixing' of the offending body part by medical expertise. The men were frequently older with multiple health problems; a diagnosis of cancer was yet one more unpleasant experience requiring attention. Consistent with current treatment recommendations, these men did not receive aggressive therapy. Hormonal therapy did not cause troublesome

side effects for these men and any reported side effects from radiation therapy were anticipated and time-limited.

Frank (1995) states that "the restitution story, whether told by television commercials, sociology or medicine, is the culturally preferred narrative" (p. 87). The belief that the body can be fixed, and that modern medicine is capable of fixing it, is central to the beliefs of our contemporary culture. For men, health and strength are critical (Courtenay, 2000), as is the financial and technologic ability to sustain it. The restitution narrative confirms that if the body breaks down it can be fixed (Frank, 1995), and it can be fixed to nearly good as new. For these men who received prompt care and treatments with few side effects a restitution story could be anticipated for their breast cancer problem was indeed, fixed.

Chaos stories

The chaos narrative describes a life that will never get better (Frank, 1995). The story lacks order, events occur without sequence or cause. Chaos stories are difficult to hear; they are anxiety- provoking and threatening, for barriers are down and anyone could imagine these unwanted stories as their own. These stories are the opposite of restitution stories, with illnesses and troubles far too complex for a quick fix.

Frank (1995) advises while illness stories often combine all three narrative types, the story can be best described by that type which dominates at the time of telling. For a chaos story to be told, sufficient time and space must pass for the teller to safely share. None of the participants' stories could be characterised as a chaos story. It is possible that as none of the men who participated in this study were newly diagnosed, undergoing

treatment or suffering metastatic disease, none of them were actively living the experience of battling breast cancer.

Theodore, whose story was overall that of a restitution experience, was able to look back and articulately describe an episode of upheaval he experienced:

> When I went into the cancer clinic they were (*starts to cry*)…they have a very good support group over there ….excuse me….anyway, they meet when you come in and they take pretty good care of you….but I didn't want to discuss this, you see… they did, these women who had the operation and all this, they're very supportive, but I didn't want to talk to them …… (*still crying*)……...and I didn't……..I just wanted to be left alone……...huddled in my corner…….they wanted to reassure you…… but it's kind of a personal thing, eh…….especially that kind of cancer…..

Frank (1995) suggests that those actively living the chaos cannot articulate the experience; it is told retrospectively with time providing physical, emotional and spiritual distance. He states that "where life can be given narrative order, chaos is already at bay" (p. 105). Theodore described the bottomless pit he felt himself to be in during the initial consultation at the cancer clinic, paralyzed and unable to articulate his needs or thoughts. Three years later, while the telling of the experience is still powerful and emotional, for Theodore it is now safe to tell.

Quest stories

The function of the quest story is an opportunity for the teller to have a voice within the illness experience (Frank, 1995). Where the restitution story tells of the triumph of medicine over the troublesome body and the chaos story is that of the lost life and lost voice of the sufferer, the quest story tells of meeting suffering head on, of accepting the illness and gaining through the experience. The illness becomes a purposeful journey, through which the teller's views of the past, present and future are changed.

Frank (1995) refers to Joseph Campbell's work "The Hero with a Thousand Faces" to describe the three stages of a hero's journey: departure, initiation and return. Campbell (1968) protrays the hero as a man or woman who has overcome personal limitations to be changed or reborn in some way. Campbell suggests:

> The hero is symbolical of that divine creative and redemptive image which is hidden within us all, only waiting to be known and rendered into life (p. 39).

Campbell describes the standard path of mythologic adventure, or *monomyth* as a story form where:

> The hero ventures forth from the world of common day into a region of supernatural wonder: fabulous forces are there encountered and a decisive victory is won: the hero comes back from this mysterious adventure with the power to bestow boons on his fellow man" (p. 30).

The hero's role and responsibility is now to return to the world, changed, to teach others the lessons learned.

Departure. In the illness story the call takes the form of a symptom – a lump, the onset of dizziness (Frank, 1995). The call is often refused, for the hero may suspect the possibility of serious illness, but maintains hope for things to turn around or get better on their own. When symptoms are such that they can no longer be denied, the hero has crossed the "first threshold". The illness is finally identified and the hero becomes suddenly aware of the magnitude of the situation.

For some men, getting to this stage and obtaining a diagnosis was a difficult experience. While male breast cancer is generally considered a disease of older men (Ravandi-Kashani & Hayes, 1998), repeated requests from these younger men for medical attention for their problem were ignored. Symptoms were an increasing concern to the participant, but frequent trips to physicians resulted in the perception of wasting the physician's time or the implication that the man was a hypochondriac:

> Brian: I was in to see the doctor and a surgeon a couple of years earlier when I had a lump. Basically, the surgeon said, "get out of my office, sometimes it's better to leave your knife in your pocket", after I hadn't been in his office more than 30 seconds. He basically kicked me out. Two years later I could feel the flesh around the bump was getting kind of firm and I knew something was going on. I suspected that this was what it might have been all along. So, 2 years later he says, "Jeez, maybe we should do something about it."
>
> Eric: Two years before, I knew something was up but had no idea what it was. I had taken my oldest son in to a hockey game in the City and had on a brand-new T-shirt with an embroidered logo on the left side. Halfway to the City I was so irritated on the left side, I had to stop and change my shirt, and it just kept

going from there. I remember having to go into the first aid room at work and getting cotton batten and a band-aid to put on top of the nipple area. Just the shirt touching it would drive me crazy. I went to the doctor 4 times - he kept telling me as you get older your body changes, and it's nothing. It got to the point it was getting embarrassing going back to the doctor, because I was wasting his time - that's how I was made to feel. This just kept going on, and I learned to live with it after while. One thing I did notice was that the nipple on the left side was rock hard compared to the other side. You know your own body…I knew it was different.

So, things went on for 2 years like that. One morning in late February of 2003 I had a shower. When I got finished in the shower I went to wipe the mirror to have a shave and I was covered in blood on the left side. I said "*this isn't normal*". I made an appointment to see a doctor – in Town you make an appointment and it's almost 3 weeks before you can get in anywhere. When I did get in, again I was telling the doctor, and you could see him roll his eyes - he wasn't interested. But when I took my shirt off, he had a look and knew right away there was something wrong.

The men whose stories could be characterised as a quest were often younger and married with dependent children. Younger age and aggressive disease meant these men were all recommended adjuvant chemotherapy, radiation and hormone therapy.

Initiation. After the confirmation of a breast cancer diagnosis, the man is faced with a new and undesirable reality. Not yet a hero, he leaves his normal life to set out

unwillingly on an unknown road of trials (Frank, 1995), experiencing suffering in various forms: physical, emotional, and social.

Surgery is the primary treatment of early breast cancer, and all participants had simple mastectomy procedures performed, with most also receiving axillary lymph node dissection (Hayes, 2002). Great variability was found among the men regarding disclosure of their malignancy. For some men, I was one of the few individuals they had told while other men felt it was important to take things in their own hands and to inform the world a man could get breast cancer:

> Theodore: When I first found out, I told everybody I had chest cancer…that I had cancer in my chest. Finally I came clean and said I had breast cancer. Like everybody else, I thought it's a woman's disease, it was nothing I ever had to be worried about.
>
> Ivan: I didn't keep it a secret, but I didn't refer to it as breast cancer, either! (*laugh*) I just said I had a lump on my chest. I don't know if this means anything or not, but I have probably only referred to it as breast cancer in one instance, that's it.
>
> Joseph: I think people today have changed, and companies are pretty good about it. I went back to work. The people back at work would ask how I'm doing and I'd say "Here, here's how I'm doing" (*demonstrates lifting up shirt*). I showed everyone at work and they'd all look at it and say "Oh my Lord!"
>
> Oscar: Well, my wife……and, um……then I think I had to tell somebody at work, 'cause I had to be away from work, ……then,……that's about it, I think. A few months later, I let my

brothers know.....and, that's about it.....I tried to keep it .....tried to keep it under the rug.....well, it seemed.....it seemed strange.....and I still do think today that.....I don't talk about it.....

Rossman (2003) differentiates between the emotional work of visible and invisible stigma; for visible stigma such as alopecia or limb amputations, the individual must learn to manage social adjustments and to integrate these changes into daily social interactions. Invisible stigma such as a mastectomy scar is routinely visible only to the individual who may choose whom, if anyone, will share this knowledge. None of the participants in this study provided any comment on the experience of alopecia. It is possible that this was not an issue as it is a current men's fashion to wear the head shaved. The less-visible but permanent stigma of the mastectomy scar was perceived in different ways by these men:

Brian: The biggest thing for me was, just being all scarred up and feeling not manly and insecure or whatever. Here's one example: when I go to the gym I always try to throw a towel over, I try to hide it. When I'm in the shower, I turn the other way – I try to not let anyone see without being too obvious. At the gym, these guys are all macho, and here I don't even have a proper chest.....

Lionel: No, I'm not ashamed of it, I'm not afraid of it, and I'm lucky. Well, I remarried after that, and I feel I'm still attractive - things like this happen to you, it's not your fault. Not like people who disfigure themselves with rings and tattoos...

Joseph and his wife relate an experience they had at a company Christmas party, where he admits to having a little too much to drink:

> Joseph: .....and the DJ playing the song was saying "let's come and get sexy". I said "well, you wanna get sexy?" I took my shirt off and started dancing - I enjoyed myself! (*laughs*). "Who is that crazy guy up there?" (*indicating imaginary others watching*)...you know, that's what life's all about!
>
> Sarah: He was saying "enjoy life! I'm not a female, but I've lost one of my boobs!" and everyone joked and laughed. They've got pictures! I'm not embarrassed. We had fun!
>
> Joseph:...it was a good time at a party...
>
> Sarah: .....I did give him a lecture the next day, just a little talk....
>
> Joseph:...now tell the truth!
>
> Sarah: It was the best Christmas party we ever had!!! (*laugh*) It had been pretty boring the first few years. We livened it up, all right! (*both laugh heartily*)

Lawrence reflects on the appearance of his chest:

> We went to Hawaii 6 months after the surgery. I was more worried for my daughters - they were a little embarrassed, I think. Vivien said one time "put your shirt on," and then Anna said "don't do that, that's ridiculous! You should have your shirt off!" And you've seen it, it's quite invasive, quite long and quite big with railway tracks. My new one here, when he went in on this side he cut off all the railway tracks...I'll show you (*lifting T-shirt and indicating to bilateral mastectomy sites*) he cleaned it right up. So, yeah, I'm aware of it. In the guys' shower at the club, once in awhile someone would say "what happened to you?"

"It was a shark!" I'd tell them. I guess I'm a little bit conscious of it, and now that both sides are done, people can sort of see. We were out in a boat at Windermere last weekend, I had my shirt off…

Grace: ..you always take your shirt off…

Lawrence: I had my shirt off and we're cruising around like that. Some sun might be good for it. I'm proud of it, in a way, because it's a milestone, no, not a milestone…a mountain that we climbed. So you know, it's good.

Participants spoke of a lack of information specific to male breast cancer, making it extremely difficult to understand their situations. They described frustration in their searches to learn more about treatment for male breast cancer, powerless to know what they were truly up against:

Lawrence: We had a copy of the pathology that was faxed to us. All of it was meaningless. Anyway, we take it in to the GP and ask her, "what is this? Is this good or bad and what does stage 2 mean?" not knowing anything about it. And she goes "Oooh, my grandmother had that diagnosis." I asked, "where is she?" "She's dead." So we really didn't get anything.

It was the first surgeon I saw who looked at me and said "Ah, this is not going to kill you…" It was the first time anyone had said anything positive about this whole thing. We had been searching like mad on the Internet every day and trying to figure out what was going on.

Eric: I found that not a lot was known about male breast cancer. They'd say, "we're going to try this, but we have no information on it". Like tamoxifen, when I was done all my treatments, "we have no data on men with tamoxifen". I

checked the Internet, and everything was about women. Everything about breast cancer is about women.

As well as a general lack of information on male breast cancer, men described stress when faced with the recommendation to receive chemotherapy. Giordano, Buzdar & Hortobagyi (2002) recommend that men be considered for adjuvant chemotherapy by the same risk categories as women (large tumor size, lymph-node positive, higher histologic grade, lymph/vascular invasion, cerbB2 positive), while acknowledging men have not participated in the clinical trials of these therapies. These younger men, often with young families at risk, felt they had no choice but to travel the long and grueling road of chemotherapy.

Eric: After some tests, I did have lymphatic invasion, and it had spread. It had gone from a level 1 to a level 4 cancer. They told me what they recommended, and I said "go for it", because I didn't really have any other choice. I had a family and had only one thing I wanted to do, to get better.

Brian: After the surgery they told me it was cancerous and they had to take out more, because the edges of the biopsy were still positive. "We have to do the full deal with the lymph nodes and everything". And then that came back, and I think there was 1 out of 10 lymph nodes that was positive, so then he said "you need radiation and chemotherapy". I was devastated. I was just separated then, and that was just such a blow to me that everything else didn't matter that much.

Arthur Frank (1995) writes of the analogy between torture and chemotherapy while reflecting on the experiences of others and his own. These men vividly described the physical suffering that they too, experienced with the chemotherapy treatments:

Lawrence: We started chemo November 1st. They say middle-aged men are the worst patients…can't handle the chemo well. I was sick the whole time – I'd have three days of feeling good prior to my next injections, otherwise was sick the whole time. So, I was a wimp through the whole process (*laugh*)! It went well, other than finding out it was the anti-nausea drugs that were making me nauseous more than anything else - I couldn't keep them down. We tried a bunch of different ones, I'd take sleeping pills every night to try and sleep, and it's such a vicious circle. Then of course, I ended up trying Gravol suppositories. You've got to keep them in for 30 minutes and my body rejected them - I would lay on my left side like you're supposed to do and just *hang on*. It was rotten.

Brian: With respect to chemotherapy, they gave me some stuff to read, but I don't know if you can ever be prepared enough. I wasn't looking forward to it….at all. The first time I took it, I got sick and I thought "this is what it's all about" and the next time when I got sick it was even worse. I don't know if you can be more prepared or not; I knew it wasn't going to be good, and it wasn't good. It was my second or third treatment - I was living by myself then, 'cause I'd moved out of my brothers' and got my own place by then - my kid was in town that weekend. I called him, 'cause I didn't even want to drive to the hospital I was vomiting so much. I actually stayed there all night.

It's been five years, now. I can't remember all the details, and you don't want to remember that stuff.

These men often described strained role expectations as they lived through their treatments. They struggled to cope while their role as provider changed, were concerned with perceptions of weakness (mental and physical) and their need to rely on others.

> Lawrence: I felt useless enough as it was. I always said to the kids "Dad can do anything", you know? But I couldn't fix this. Suddenly, you're in need of care and attention and support. It's a hard place for a man to go…to lay back and say, I do need this.
>
> Eric: When you go through that, you're not producing at work, so are you productive at home? It does bother you, like, am I carrying my fair share of the load? So when I wasn't working, that was fine, that part I had to put on the back burner. But when Enid was working every day, she took on a few extra hours to help out, too. I felt as long as she was working, she shouldn't have to do any cooking, any cleaning, any laundry. And it may sound trivial, but I was so beat through the treatments. I'd use my day-timer and write a list of things to do each day, and she'd come home from work and supper would be ready for her each day. She never had to worry about laundry or anything like that.

The Return. After his journey, the hero is transformed. He has changed through the experience, looking backward at his past and forward to the future with different eyes. The hero is now a "master of two worlds", and has "been blessed with a vision transcending the scope of normal human destiny" (Campbell, 1968, p. 234). He has new insight and wisdom; gifts earned through trials and difficulties endured, earned not through force but through tenacity. In the illness story, the hero returns, no longer ill but marked forever by illness (Frank, 1995).

The men whose experiences I have characterized as quest stories tended to be middle-aged (Levinson, 1986). Several authors have studied important life roles and social expectations for men in the age group of 36 - 45 (Cournoyer & Mahalik, 1995; Theodore & Lloyd, 2000) concluding that achievement, power, and competition are critical means of demonstrating masculinity, typically carried out in the work environment. Not surprisingly, middle-aged men frequently struggle to balance success in the workplace versus the needs and expectations of their young families (Theodore and Lloyd, 2000; Helgeson, 1995).

Before their diagnosis, these men spoke of their careers as having been the priority in their lives. Their experience with cancer obliged them to re-examine what their priorities in life really were.

Lawrence: Well, I'm a CEO of a big company here in town. You travel the world and do lots of big and great things, which were sort of a priority. But now, work's really down....maybe number 10. Really, I don't even know where it sits, because it's completely different. That's not the focus. The focus is that every day needs to be spent properly and to go where your heart takes you, sort of thing. And the kids...I've been driving the kids to school ever since and picking them up. Before, whenever Grace would ask for help, my first reaction would have been "NO". Now it's "No, I'm going to do this – you might never get the chance to do this again". That's what goes through your mind.

Eric: Since the diagnosis I spend a lot more time with my family. Right up until the time I went into the hospital I'd work 900 – 1000 hours a year overtime. I still work some overtime, but last year I had 50 hours. I bank it and take it as time off.

I don't take the pay anymore and I don't miss it. I'm not any less dedicated at my job, I just don't work the overtime. I spend a lot more time doing things; I've gone on ski trips with my son and different things with the kids that they're interested in. I find the overtime is not important anymore. I'm still pretty driven; before at work I was always striving for one notch better in the company. I'm not doing that anymore. It's more important to me to take a couple of those overtime hours and go to the lake – I'm not after that next position. At home, I spend more time with the kids, but I haven't really changed a whole lot. Some people say it's a life-altering experience or whatever, but I haven't changed like that. What has changed is that we try to enjoy today more than we did before. I just bought a boat and a new vehicle. We still put away for our retirement, but enjoy our life while we still have it. Because I still have it in the back of my mind, I don't let it bother me too much, but I had it once….will it come back? That always is in the back of your mind.

These men stated that before their diagnosis, the struggle to 'get to the top' of the corporate ladder was the major focus in their lives and that participation in family life was not considered (and sometimes actively avoided). They speak of their changed perspective on family relations, now a priority.

Eric: Going back, I wouldn't change anything. I've often said that, and people look at you kind of funny. I had cancer but I wouldn't change it because it's brought other things forward, it's brought the family closer. We've learned to deal with things a lot better. I wouldn't go back and change anything. You have to

experience what life gives you in order to be able to move on and be stronger with it.

Lawrence: But it's been a great experience in the end - because every day is wonderful. I mean, it's got me very focused, because in the cancer world you meet a lot of people who are dying. So I've changed my views on life....RADICALLY! It's been....

Grace: ...it's been great! (laugh)

Lawrence: Yeah, it HAS been great...it's the best thing that's ever happened to me in that regard! Because, with watching people die it's a constant reminder. I was involved with dragon boats and these gals, so many of them were at funerals and stuff. What I got out of that was getting involved with the breast cancer foundation. It's great awareness...that part's great.

In addition to taking a more active role in the relationships in his family, Lawrence has become involved with a provincial breast cancer foundation:

We just did a video, with me in the background of it. The video is all about everything else, with all the other effects discussed...the spouses, the kids and men getting it. That's what I do ..... you hear a roar around the room when I get up and tell them that it's me...it's ME with the breast cancer!

Myhre (1999) states that goals of the breast cancer movement are to mobilize public support for breast cancer issues, to increase research funding for breast cancer, to influence breast cancer policy, and to change the shape and content of scientific research in the prevention, treatment, and cure of breast cancer. Lawrence has made himself visible as a man with breast cancer and potentially an agent of change. By demonstrating

to the public that men can get breast cancer too, he may succeed in changing perceptions, policies and research to benefit others.

While support groups have had a longstanding and successful history for women who have survived breast cancer, support groups for men are poorly attended. Even as many of the study participants were interested in providing support and community involvement after recovering from their experience, none of the twenty participants expressed interest in participating in traditional support groups before or during their treatment.

> Garth: No, I haven't even gone to a prostate one - they have them down at the prostate center. I guess if I had need of significant support, it would be there....I think women tend to lean on one another more than men do, by nature, not just for breast cancer. Men tend to be isolated a lot more, or choose to be isolated a lot more, I think.

Men in a common-law or marital relationship will rely on their wives as their primary source of support (Keller & Heinrich, 1996) and are unlikely to seek out social support (Nicholas, 2000; Vaartio, Kiviniemi & Suominen 2003). Without exception, men in this study relied on their wives (if married) as their sole source of support. However, some of the participants recognized that support in an acceptable form might have been useful. Hector had felt he had no emotional concerns related to breast cancer, but while telling his story realizes his admission to hospital for depression coincided with the period immediately after diagnosis:

> And the thing was, I was fine. Until after I had the breast cancer - I guess maybe the cancer did hit me somehow. I guess it was after that, just shortly after that,

when I got so depressed. As far as I had been concerned, I just shrugged it off. But subconsciously, it must have been affecting me, although I didn't think it was.

Lawrence reflected on his needs for support and information. He felt that having the opportunity to speak to a man (or woman) who had faced similar problems and treatment choices would have been helpful:

> I was just frantically looking for information - am I going to die? Give me some probabilities here - I want to mechanically understand it. Even if it's 50/50, at least now you know and you're not running around worrying about it. So, I'd recommend to somebody that get connected, whether it's a man or woman with someone with a similar diagnosis.
>
> I'd tell people to hang out more at the Cancer Clinic, I should have been there earlier. Before the chemo, we should have gone to psychosocial services, but nobody could tell me what I was up against.

While Eric now provides telephone support for a man in another province, he considers the supports he utilized during his experience:

> I don't know if support groups would have been helpful for me. I didn't think I needed to talk to anybody. I had one person - I should say I had someone I could talk to. She used to work for me in another town and had exactly the same cancer. It was helpful to find out, because all the side effects that I went through, I would wonder 'does everybody experience these side effects?' and she had exactly the same side effects.
>
> If I knew a man who had a positive biopsy, I'd suggest he work on attitude.....attitude and communication. The one that I'm helping with in

Manitoba, I think he's alright with attitude, but he doesn't tell his wife anything. And if you're married, it's a partnership. And you've got to keep your wife informed what's going on, you have to. Because, like I said before, I think they suffer more than I suffered because they can't do anything for you. Their best way is to prepare meals or try to do something that's going to help, but you've got to let them in. And if they need to cry, you have to let them. Like you just have to be there for them - it's got to be open. Wouldn't it be sad if it didn't work out and you passed away and you didn't let your wife in to help? Now they're left behind with a whole lot of guilt. I think you've got to let them be part of it.

Brian: For another man diagnosed with breast cancer, I'd give encouragement….I'd tell him that he'd get through it. Not to worry, if he had any questions, to come and talk to me. I'd call him often, because he might not want to call me because it would be like complaining, so I'd call him. Just to see how he's doing and to listen to him. I'd let him ask or encourage him to ask questions, just for support – to get it off his chest. That's what I'd do.

Support is composed of three categories: instrumental support including financial and material resources; informational support including technical information and advice; and emotional support providing opportunity to acknowledge and share feelings (Helgeson, 1995). Consistent with the findings of Kiss & Meryn (2001), these men indicated their strong preference for informational resources on topics such as prognosis, treatment options and side effects, which unfortunately were frequently unavailable for them. None of the men commented on issues of instrumental support, as they all had sick leave benefits and publicly funded treatments. With respect to emotional support, the

participants speak little of sharing their feelings; rather, they express concern about their wives' feelings or that others might think they were 'complaining'. By acting as informational supporters for other men with a cancer diagnosis, these men are demonstrating the type of support they would have wished to receive – that of another man who has 'walked in the shoes' of the breast cancer experience:

> Lawrence: I'd like to talk to a guy who's been through my experience, you know? I'd like to talk with some guys - if I had a way to talk to guys and see how they're managing, 'cause it's an ongoing process.

In retrospect these men state that their experiences, while difficult to endure at the time, have vastly improved their lives. These men have had the opportunity to reflect on what it means to be a man, a man who has experienced breast cancer. Consistent with Gordon's findings with men who experienced testicular cancer (1995), these men now consider themselves to be more concerned with relationships, more empathetic and emotionally expressive. They have been transformed to heroes, and better men for surviving what society commonly perceives as a 'woman's' disease.

Chapter 6 – Interpretive Discussion

In the telling of their experiences, the men who participated laughed and cried with me. They described fear, joy, pain, anger, regret, gratitude and hope for the future. As described previously, I have considered their stories in the context of the three general forms described by Frank (1995). I have also considered the experiences identified by the participants as important in the context of the current literature and provide potential recommendations for future public information and health initiatives.

Story forms observed

The forms observed within our sample included both restitution and quest stories. Older men who participated in this study most often told a story of restitution. These men described their experience with breast cancer as a brief medical event where the problem was identified, recommendations made and the operation a success. Consistent with current treatment recommendations, older men did not receive aggressive systemic therapy. Radiation and hormone therapy or hormone therapy alone were prescribed as adjuvants to surgical treatment, therapies that are time-limited and easily concealed.

The men whose stories could be characterised as a quest were often younger and married with dependent children. Younger age and aggressive disease meant these men were all recommended adjuvant chemotherapy, radiation and hormone therapy. It is difficult to determine what factors contributed to the different story forms observed: the personality of the participant; the arduous experience with aggressive chemotherapy; struggles with a mismatch of life role expectations versus coping with side effects of treatment (Cournoyer & Mahalik, 1995; Theodore & Lloyd, 2000), a combination of these or possibly other yet unknown factors.

It is clear that men describe a diverse range of experiences, needs, hopes, fears, and expectations within their cancer journeys. Health professionals must adopt a sensitive approach and carefully evaluate men's needs continuously, avoiding the pitfalls inherent in our society's stereotyped social expectations (Courtenay, 1998; Seymour-Smith, Wetherell & Phoenix, 2002).

Diagnosis, disclosure and body image

While there is abundant literature suggesting that men are unlikely to voluntarily seek attention for a health problem (Seymour-Smith, Wetherell & Phoenix, 2002; Keller & Henrich, 1999; Courtenay, 2002; Sandman, Simantov & An, 2000), none of the respondents admitted to knowingly delaying attending their physician. However, several participants, particularly younger men experienced difficulty getting the attention they needed from their doctor, resulting in major delays in diagnosis. They recognized symptoms as a problem, but frequent trips to physicians resulted in the perception of wasting the physician's time or the implication that the man was a hypochondriac. Two of the six participants in France's (2000) study had similar experiences, necessitating assertive statements or changes in physicians. The participants in this study voiced frustration and in some cases regret that their cancer was not discovered earlier. Some clinicians argue that delays in diagnosis are insignificant, as breast cancer is believed to develop sub-clinically over years. However, systematic reviews have shown significantly worse survival outcomes for breast cancer patients who experienced delays in treatment interventions after onset of symptoms (Richards, Westcome, Love, Littlejohns & Ramirez, 1999). While these reviews included female patients only, the benefits of early diagnosis and treatment would also be expected to apply to men.

The failure of physicians to promptly attend to a man's concern with a breast lump has not been examined in the literature. Shinagawa (2000) points to the ongoing problem of 'institutional racism', stating that preconceived notions and personal attitudes of health care providers continue to impact strongly and negatively on the health of minorities and the medically underserved. Her review of cancer surveillance data revealed that advances in therapy have not benefited those breast cancer patients in minority and medically underserved communities, concluding that a major barrier factor is continued societal and institutional racism.

Institutional racism has received attention and discussion in other settings including those observations of Schulman et al. (1995) showing physicians were significantly more likely to refer male and white patients for cardiac catheterization rather than women or colored patients presenting with identical symptoms and health insurance. It is possible that lack of continuing medical education in the area of breast cancer for community physicians has contributed to the difficulties experienced by our participants. As Lawrence stated, "…male breast cancer needs to be on the doctors' list. No matter how low the risk is, even half a percent….you still have to pay attention to it." Participants felt that awareness campaigns were necessary for male breast cancer, targeting both professional and public audiences (Iredale, 2006). Suggestions included television commercials and men participating in athletic fund-raising events such as dragon boating, golf tournaments or walks to help raise awareness of male breast cancer.

Great variability was found among the men regarding disclosure of their malignancy. For some participants, disclosure of their diagnosis was limited to those from whom he sought support: his wife and immediate family (Vaartio, Kiviniemi &

Suominen, 2003; Kelsey, Owens & White, 2004). It took time and courage for them to feel comfortable sharing the information with other family members and friends. As Theodore stated, "When I first found out, I told everybody I had chest cancer…that I had cancer in my chest. Finally I came clean and said I had breast cancer… Like everybody else, I thought it's a woman's disease, it was nothing I ever had to be worried about." Reluctance to share the diagnosis was often related to the perception that breast cancer could not be experienced by a man. A sense of isolation was often evident while these men told their stories. On the other hand, others made a concerted effort to educate others as much as possible. As Joseph stated: "I showed everyone at work….they'd all look at it and say "Oh my Lord!" and Lawrence: "We just did a video, with me in the background of it." Again, these men re-iterated the necessity of public service campaigns indicating that breast cancer was a man's problem, too (Iredale, 2006).

Similarities and differences were experienced by our participants and those of France et al. (2000) in their descriptions of body image. Some participants in each study experienced negative thoughts about exposing their chest in public or participating in previously enjoyed activities like swimming. As Brian confided, "when I'm in the shower, I turn the other way – I try to not let anyone see without being too obvious. At the gym, these guys are all macho, and here I don't even have a proper chest….." A healthy male physique embodies the socially valuable characteristics of toughness, competitiveness and virility (Gerschick & Miller, 1995). Research into helpful supports for men with these post-mastectomy concerns does not yet exist.

In contrast with these experiences, some participants in this study voiced very different opinions about their bodies. As Lawrence shared, "I had my shirt off and we're

cruising around like that. I'm proud of it, in a way, because it's a milestone, no, not a milestone…a mountain that we climbed…so you know, it's good." These participants re-framed their thoughts and changed bodies into a positive and constructive experience. Similar descriptive experiences and thoughts about body image among men with breast cancer have not been published. As commonly used instruments to evaluate body image among breast cancer patients have been validated exclusively among female cancer patients, caution should be exercised when interpreting results of studies where such measurement tools are applied to the opposite gender (Hopwood, Fletcher, Lee & Al Ghazal, 2001; Brain, Williams, Iredale, France, and Gray, 2006). Clearly, further research is necessary to examine how men cope with their changed bodies after surgical interventions for cancer and how to best support them.

Information

As male breast cancer is less common and accounts for less than 1% of all breast cancer cases (Hayes, 2002), randomized clinical treatment trials have not been conducted with this population. Rather, treatment recommendations for men are considered by the same risk categories as women (Giordano, Buzdar & Hortobagyi, 2002; Hayes, 2002). The participants voiced frustration while searching for treatment information for male breast cancer and a lack of breast cancer information specific to men. This was similar to the observations of France (2000) where all six men received no written information about the condition or treatment of male breast cancer.

In this study, the men who were recommended to receive chemotherapy with numerous potential side effects and complications felt the lack of specific information contributed to their emotional distress and apprehension. As Eric stated, "I found that not

a lot was known about male breast cancer. I checked the Internet, and everything was about women. Everything about breast cancer is about women." The participants did not expect a male-specific breast cancer brochure; rather, they expressed the reasonable wish that male breast cancer information be included in existing written general and treatment information about breast cancer. On-line resources could also be developed, available country-wide. Allowing men to participate in treatment trials or performing retrospective reviews of cohorts of men within large provincial databases would provide increased information on the risks or benefits of various treatments.

Support

Moynihan (2002) states that we know little about what supports appeal to men with cancer, as their participation in psychosocial oncology research has not been actively sought. While many authors and professionals recommend emotional expression and psychosocial counseling to promote good adaptation (Nicholas, 2000; Zakowski et al. 2003) it is still not clear whether or not men with cancer benefit. Both our participants and the men studied by France (2000) depended on their wives (if married) as their primary source of support. As well, both groups consistently indicated disinterest in participating in cancer support groups as they are currently perceived. This is congruent with the observations of several authors (Keller & Heinrich, 1996; Nicholas, 2000; Vaartio, Kiviniemi & Suominen 2003). Few participants spoke of their own emotional concerns; rather, they expressed worry about their wives' feelings or that others might think they were 'complaining'. None provided any suggestions or recommendations for emotional support resources outside the family. These observations are consistent with the opinions of Nicholas (2000) and Courtenay (1998) who suggest that emotional

expressiveness or asking for psychosocial help threatens and magnifies masculinity issues. Further research in the area of formal support services for men is critical in our changing society given increasing rates of cancer and chronic disease, escalating divorce rates, single parent families and the increasing mobility of our population.

While these men struggled through their treatments, they frequently described role strain while their responsibility as provider changed, were concerned with perceptions of weakness and the need to rely on others (Theodore and Lloyd, 2000; Helgeson, 1995). As Lawrence eloquently described, "It's a hard place for a man to go…to lay back and say, I do need this." These topics are difficult for a man to articulate while embroiled in the experience, for as Eric reminisced, "I didn't think I needed to talk to anybody". In retrospect, participants often conceded that support would have been helpful. It is critical that health professionals develop a safe and therapeutic environment to raise such topics with men, normalizing common worries such as side effects and social perceptions and expectations.

Rather than emotional support, these men frequently indicated strong preferences for informational support (Kiss & Meryn, 2001; Shapiro et al, 2004) on topics such as prognosis, treatment options and side effects, which had been unavailable for them during their experience. Several study participants expressed the wish that they had the opportunity to speak to a man (or woman) who had confronted similar concerns and decisions. Many indicated interest or were already providing support to men with a diagnosis of breast or other cancer. This is in stark contrast to France's (2000) findings, where none of the six men interviewed had any desire whatsoever to speak to another man about breast cancer. It is difficult to know the reason for this observation. Patient

characteristics are not described in France's study; it is possible the participants represented a different age group or received different treatments.

While participants indicated interest in speaking to another with a similar breast cancer diagnosis and treatment, issues with confidentiality and personal information are apparent. One potential solution could be an on-line support website, where men could voluntarily sign on and participate. Web-based support groups are already well-established for female breast cancer survivors and prostate cancer survivors. The internet is a major source of information for Canadians, as an estimated 7.9 million (64%) of the 12.3 million Canadian households had at least one member who used the Internet regularly in 2003 (Stats Canada, 2004). Health information is frequently sought on-line, with almost two-thirds (65%) of households seeking such information, the third most popular use after e-mail and general browsing. Clark (2001) states that the trend for people to go on-line for healthcare information is typical of the general consumer trend of the 1990's – increased self-reliance in all areas of life. The Internet allows the user an environment to direct their learning experience by providing information when desired – appealing and consistent with adult learning theory. Home internet use also allows for a safe and non-threatening environment where men might feel comfortable searching for information or psychosocial support for male breast cancer. Some study participants described searching the internet for male breast cancer information, only to be disappointed. It is possible that increased awareness and activism among male breast cancer survivors could lead to the development of on-line support and informational websites.

Changed lives

Before their diagnosis, several study participants defined their career as the priority in their lives. The struggle to 'get to the top' of the corporate ladder was their major focus and that participation in family life was not considered (and sometimes actively avoided). Their experience with cancer obliged them to re-examine what their priorities in life really were. Frank (1995) quotes a participant in his research who states the true lesson is "living as if it really mattered, which it does" (p. 141). The storyteller brings back from the illness experience the responsibility to teach others, to make their suffering useful. Several participants indicated that however difficult living through the cancer experience was, their lives were greatly improved afterwards. They became much more involved in everyday family life, less interested in their careers and placed more value on personal growth and relationships. As Eric stated, "going back, I wouldn't change anything. I had cancer but I wouldn't change it because it's brought other things forward...you have to experience what life gives you in order to be able to move on and be stronger with it." Lawrence echoed his feelings, "it's the best thing that's ever happened to me in that regard!" These men have had the unique opportunity to reflect on what it means to be a man, a man who has experienced breast cancer.

These new perspectives were not described in the sample of men studied by France (2000). It is possible that the list of questions that guided France's interview process did not allow for open-ended exploration of the participant's point of view, missing these and likely other elements that may have been significant to the respondent. The exploratory design utilized in this study imparts strength by encouraging the men to describe what was significant about their experience with breast cancer while these areas

were explored, allowing for the sharing of experiences and development of new knowledge.

Gordon (1995) described similar observations of testicular cancer survivors within a subgroup of men with less traditional views on masculinity. These men considered themselves to be more concerned with relationships, more empathetic and emotionally expressive since their cancer experience. It is possible that different perceptions on what defines masculinity may contribute significantly to a man's overall experience and perspective of life after cancer. Hegemonic masculinity, defined by male dominance over women, physical strength, proneness to violence, emotional inexpressivity and competitiveness (Sabo, 2000) likely has a profound effect on a man's outlook and needs when experiencing serious illness. Further research examining men's beliefs about masculine attributes and how this relates to coping during and after a cancer diagnosis is warranted.

Conclusion

Frank (1995) states that the illness story serves three important purposes: to describe the teller's re-ordering of the life story; as guidance for others who follow; and, to provide caregivers with an understanding of the illness experience. The storyteller brings back the responsibility to teach others, to make their suffering useful and meaningful. To heal, the storyteller must speak; to learn, we must listen.

Arthur Frank dares us to listen. "One of the most difficult duties as human beings is to listen to the voices of those who suffer" (1995, p. 25). As health professionals, our responsibility is to value the lives and stories of those we attend, to take note of nuances and meanings. And by listening, we may learn from the experiences of others the lessons

that are really important in this life, and live "as if it really mattered, which it does." (Frank, 1995, p. 141).

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Appendix A – Ethics Approval Letters

Alberta Cancer Board

Provincial Office
1220, Standard Life Building
10405 Jasper Avenue
Edmonton, Alberta
Canada T5J 3N4
Tel: (780) 412-6300

ACB Provincial Office
Edmonton

Tertiary Cancer Centres
Cross Cancer Institute
Tom Baker Cancer Centre

Associate Cancer Centres
Central Alberta Cancer Centre (Red Deer)
Grande Prairie Cancer Centre
Lethbridge Cancer Centre
Medicine Hat Cancer Centre

Community Cancer Centres
Barrhead
Bonnyville
Camrose
Canmore
Drayton Valley
Drumheller
Ft. McMurray
High River
Hinton
Lloydminster
Peace River

Epidemiology, Prevention & Screening
Calgary

Medical Affairs & Community Oncology
Edmonton

Research
Edmonton

Alberta Cancer Foundation
Accepts donations in support of ACB facilities and programs.
Toll-free: 1-866-412-4222

www.cancerboard.ab.ca

ALBERTA CANCER BOARD

22 June 2005

Edith Pituskin
Medical Oncology
Cross Cancer Institute

Dear Edith,

RE: ETH-22031: The Experience of a Sample of Canadian Men with Breast Cancer

Thank you for submitting an application for reciprocal approval for the above named study. I am pleased to grant approval to your participation in the above noted study on behalf of the Research Ethics Board (REB). The following documents have been reviewed and approved as of 22 June 2005:

- Protocol (dated 30 May 2005)
- Letter to Patients from the Alberta Cancer Registry
- Consent form dated 30 May 2005
- Health Research Ethics Approval Form dated 6 June 2005

Please note that this approval is based on the following conditions:

- a copy of the informed consent form must be given to each research subject and consent obtained prior to enrollment on the study;
- if there are any other changes to the protocol or consent form during the year, or if any serious adverse events to the treatment are found, a letter describing the changes/reactions must be forwarded to the REB as per the Alberta Cancer Board Policy J3.11b together with an updated consent form;
- an Annual Renewal form must be submitted two months prior to the deadline date of **21 June 2006** (one year from date of review), containing the information as per our annual renewal form;
- a Final Report must be submitted at the termination of the project.

The deliberations of the REB include all elements described in Section 50 of the Health Information Act, and this study was found to be in compliance with all the applicable requirements of the Act. It has been determined that consent will be obtained from study participants for disclosure of the health information to be used in the research.

The Alberta Cancer Board REB, complies with the following guidelines and regulations:

- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans;
- Health Information Act which has been proclaimed on April 25, 2001 in Alberta;

- Health Canada, as defined in C.05 (Part C Division 5) (1024-Clinical Trials) of the Food And Drug Regulations-Amendment and the Therapeutic Products Directorate Guidelines/ICH Harmonized Tripartite Guidelines-Good Clinical Practice: Consolidate Guidelines;
- National Institutes of Health-Code of Federal Regulations (USA); and
- Our institution has been approved by the Office for Human Research Protections in the United States.

Please accept the Board's best wishes for success in your research.

Sincerely,

Scott North, MD
Chair, Research Ethics Board

/br

PC: CPA
Brenda Bird-Cantelon
OIPC

Health Research Ethics Board

213 Heritage Medical Research Centre
University of Alberta, Edmonton, Alberta T6G 2S2
p 780.492.9726 (Biomedical Panel)
p 780.492.5332 (Health Panel)
p 780.492.0830
p 780.492.0839
f 780.492.7838

June 3, 2005

Bev Williams
Faculty of Nursing
3rd Floor CSB

File# B-190405

Dear Ms. Williams,

Re: **The Experience of a Sample of Canadian Men With Breast Cancer**

Thank you for Ms Pituskin's correspondence of June 3, 2005 which addressed the requested changes to the above-mentioned study. These revisions have been reviewed and approved on behalf of the Research Ethics Board. Your approval letter is attached. The following additions to the study have also been approved:

- Modified Information Sheet with Consent (version date May 30, 2005)
- Covering Letter from the Alberta Cancer Registry

Next year, a few weeks prior to the expiration of your approval, a Progress Report will be sent to you for completion. If there have been no major changes in the protocol, your approval will be renewed for another year. All protocols may be subject to re-evaluation after three years.

For studies where investigators must obtain informed consent, signed copies of the consent form must be retained, and be available on request. They should be kept for the duration of the project and for a full calendar year following its completion.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health or other local health care institutions for the purposes of research. Enquiries regarding Capital Health administrative approval, and operational approval for areas impacted by research, should be directed to the Capital Health Regional Research Administration office, #1800 College Plaza, phone 407-1372.

Sincerely,

Charmaine N. Kabatoff
Administrative Coordinator
Health Research Ethics Board (Panel B)

Appendix B – General Questions

1. When did you first know something was wrong?
2. What was happening in your life then, and what has happened since?
3. If you could go back in a time machine, what advice would you give yourself?
4. What advice would you give others (other men, families, health care professionals)?

Appendix C – Remaining Sixteen Stories

Peter's Story

I am welcomed by an older couple living in retirement village in a town in Southern Alberta. Both appear comfortable and unruffled by a visitor. Their suite is decorated with many pictures of adult children, grandchildren and great-grandchildren.

I first noticed it about 15 years ago – we were still on the farm then. I noticed my left nipple had changed. It was becoming almost inverted, drawn back in or something. And there was a slight hardness around it, about two and a half inches across. So, I showed it to my doctor. He looked at it and said, 'I want the surgeon to see this right away,' and within a few days I talked to our surgeon who was here in town. He looked at it and said he would set up an operation when he would have the pathologist there. They would start the operation and if the pathologist said it was cancer, they would go ahead with the whole operation. I said, 'yeah, let's do that'. So we did.

I had the operation, and there was nothing much to it. I didn't have any pain or anything like that. They decided to give me radiation as a precautionary measure. They gave me 25 treatments of radiation, I think in July. The operation was in May, and it was July when I got the radiation treatments. Then they recommended tamoxifen. So I started taking that. I can't remember how long I took that - I guess about a year then I stopped. That was it, as far as any effects.

I know there's not very many cases of men's breast cancer. I realized there was some kind of stigma attached to it, or something or other. Once in awhile, you'd hear comments like, 'oh breast cancer - I thought your voice was getting a little different' (*imitates falsetto*), and things like that. But, I didn't care. All of our neighbors and friends knew. Our kids never said much of anything. Well, I didn't take it very seriously, and I don't think they did, either. We had a pool at home. I never felt uncomfortable going without a shirt, not that I did that much anyway. I never really gave it a thought.

In the last two and a half years here they found I have bone cancer. They think it's from the breast cancer. The first bone scan showed what they call innumerable lesions, on my spine, my pelvis and arms and shoulder, especially the right shoulder and the right hip. I got some radiation to the shoulder and the hip and that's when I started using the cane. It wasn't very long after that the pain totally disappeared and has never come back. It's amazing – I'm sold on radiation. And the bone scan reports are getting better all the time. It appears that it's under control and I feel pretty good, I'm OK. The oncologist says I'm in pretty good shape.

At the cancer center, there was nothing there for men. We've never saw any brochures about men having breast cancer, and still don't. It should be advertised. I remember my doctor asking me if I'd ever had an injury, or anything. Well, how would I know? I've been knocked around quite a bit.

There's one thing I don't know, it's whether I should be exercising or not. It seems to me that with my kind of a problem, a lot of exercise might not be a good idea. I still take a 15 or 20 minute walk every morning. I was concerned that maybe if I did too much, things might get sore. I also find that I get tired easily; about the most strenuous thing I do is go fishing.

With support groups, I haven't done that, and would I be interested in doing that? I don't think so, I'm pretty confident in my doctors and my cancer specialists. My regular doctor told me I'd never die of cancer. I'm on medication for my prostate difficulties, and it seems to be working well. I've got three major problems: bone cancer, a grossly enlarged prostate and COPD. I'm taking treatment for COPD and tried so many different things, puffers you know, all for people with asthma. Now I've got something that works - doesn't say anything about asthma on it and it seems to help me.

I don't know what I could have done to prevent it, I don't think anything. I guess the only advice I could give anybody would be to just keep calm, get all the treatment you can and have confidence in the system. I'm totally confident in the treatment I'm getting and everything.

Paul's Story

It's a beautiful summer afternoon and I am visiting an older couple in comfortable home in the City. You can see that many years of care have gone into their home and yard, with a meticulous back terraced garden and decorated home. Many pictures of family and friends are scattered through their home.

It seemed like it was all women, even when you went for a mammogram. I get one once a year, and the lady oncologist that I talk to after finishing five years of tamoxifen. One of the things, it was almost 6 years when I got a new oncologist, she said 'you should only have had five years of tamoxifen,' so that was that. But there were no adverse effects.

It was just like that (*snaps fingers*). I got up one morning and I forget, yeah I was moving around in bed, trying to wake up. I thought I had something in the pocket of my pyjamas, a marble or something, maybe from playing with my grandkids or something like that. I had a look at it and it was a lump about the size of the end of my finger and sticking right out. There was nothing there before - I'm sure of that, because every morning you shower and wash up and I would have found it. So it just popped out like that. It was 1994, yeah. So I went to see the doctor, he did the usual check-up, took me in and put a squeeze on me. And then, did they take a biopsy? Yeah, then about a week later, the surgeon called me to say I had breast cancer.

I had no idea men could get breast cancer, ever. There was no breast cancer in either paternal or maternal lines that any of my older cousins knew of. So I can remember being a bit shocked by that. One man at our church found out he got cancer, and he was gone in about 3 months. But I got over that, whatever's going to happen is going to happen. The surgeon operated and took that and some of the nodes under here, too. But after that was all uphill. Nothing adverse at all. I had no problems at all - all the muscles were OK.

I had to go to the cancer center, of course. They did say we often give chemo or radiation, but they didn't think I needed it, just tamoxifen. They're really good people, nice people there. After that, I went back every 3 months, then every six months for awhile, then yearly. And I've had no problems of any kind associated with it.

There wasn't any written information about men's breast cancer. All the information I got was that there was maybe one male in about one hundred or two hundred cases - they didn't even know for sure. That year I think they said they had 2 men with breast cancer. They weren't trying to keep anything from us. The one thing I had was that bone scan a few months afterwards. They said that because there's so little tissue there for men that it's quite often that it goes into the bone. So that was kind of a trying time, waiting for the results of that to come back. We were very relieved that there was nothing there and in 1994, there wasn't the wait period that there is now.

We told our sons, our in-laws and relatives who were close that this was what we were facing. I know some people don't tell anybody until after everything's all over with. But

we put it out in the open right away. It was normal and natural for us to tell everybody what was going on. After all, we might have received a few extra prayers.

I don't know if talking to another man would have helped me at the time. I think the best person to talk to is your own doctor, who will get things, action going right away. The doctor at the cancer clinic, too, he was very helpful. He was sort of the head of the program. He was a very unassuming kind of man and told us everything he could about men's breast cancer. He said all the evidence they had was that the medication they were giving me would give the best results - he never even spoke as if there was an alternative. And he never had to talk about chemotherapy or radiation, because this seemed to be doing the job.

I don't worry too much about it coming back. I've long since quit worrying about anything like that. It has never had any adverse effect on me from the point of doing anything I wanted. I generally have done quite a few activities, and I've been on my stationary bike…I've done that for a long time. Plus calisthenics and so on. A long time ago the RCAF developed a series of exercises for people in the service. The company medical doctor became aware of these and he gave the booklets out to everyone - there were 5 basic exercises. I fall off it now and then. I also try to golf a little more.

It was 1994 I was diagnosed with breast cancer, then 1996 with heart disease, 1997 a bypass; so there's been a number of challenges. The only thing that's noticeable is that the nipple's gone, otherwise it's not a big deal. It really hasn't bothered me. And the scars from the other operations are nearly invisible, too and that's in the good old days when they had to cut everything. Some of the things, you have to laugh about, really. I think I'm blessed.

When the doctor told me I was in trouble with my heart, I had gone to see him because I had an awful cough for awhile. My wife had taken the bus out to B.C. to visit her sister and had told me to see the doctor about the cough. So he did the usual routine, then said "I want you to get an ECG" - this was around 5 o'clock or five-thirty. So I came back with the ECG in my hand and gave it to him. He had a look at it and said, "you're going to emergency, now!" I thought, "I guess, OK". He wouldn't let me drive, so I took a taxi. I called my son to pick up the car and let him know what was going on and my wife was on the bus back right away. But that's another story!

I don't think the heart operation hit me as much as the cancer operation, it was the idea of cancer. My first wife died of cancer, very slow and difficult. It was off and on for about 10 years for her. I don't know if there's been a lot of cancer in her family, maybe I didn't want to know about it.

The only advice I could give someone is just do what the doctor tells you, period. And I would tell him what happened to me and we could do some praying if he was accustomed to that. There's a certain amount of what's gonna be is gonna be, but you need to do the best you can. I'm fortunate - I've got a great cook, and more! (*laughs and hugs wife*)

Joseph and Sarah

I am visiting a middle-aged couple living in a quiet neighborhood in the City. Both are enthusiastic and interested in the project.

Sarah: …I'd like the people on TV to talk about men. Nobody has mentioned men.

Joseph: I don't know, .I don't think men get the same breast cancer as women - it was new to me. I know a lot of women lose one or both of their breasts. I had no lump in mine, just a change in the nipple. It went a little bit round and started to suck its way back into the body. It was an odd color, too; it was totally totally different from the other nipple, you know. I didn't tell the wife right away. She'd had problems with her mother who was very sick, but I did tell my daughter. My wife had too much on her plate at one time.
So I thought something was wrong somewhere, so that's when I went to see my family doctor. He got in touch with the specialist I was there ASAP. No ifs ands buts or nothing - they got me right in there. I saw the family doctor in June and it was all done in August. It was just a one-day operation, in and out of the hospital. I was wide awake right afterwards. I didn't want to lay around all day, so I got up right away. The doctor said "I'll let you know how it's going the next day" and I said "don't you worry, I'm going home right now". I thought I might be in there awhile, like some people. I don't think my case was serious, I think it was a fluke and that was all.

Sarah: He wanted out the next day. I was up there at 6 a.m. having coffee with him and he didn't want to stay; he doesn't like hospitals.

Joseph: I was the same getting my varicose veins taken out here. The same day, I came back from recovery. As soon as I woke up I was up for a walk. The nurse asked me where I was going - I said "for a walk!" "you just had an operation!" "I don't care….I'm going for a newspaper and a cigarette…I'll be back in half an hour!" Even Sarah was surprised….she saw that I was awake when I came back from the operating room.

Sarah: He kept saying "I'm back, I'm back here. I'm fine, I'm awake!"

Joseph: I went to the Cancer Clinic and got pills and a clean bill of health from the doctor there. I don't think the cancer went very far; I just got some pills. I don't remember exactly what kind of cancer it was. They didn't give me any written information. They told me how long to take the pills. The pills are so it doesn't re-occur again, which is good, you know. They never said anything - just go back and live a normal life and I said thank you very much. I know some of the females, they take a long time to get over it. Because they lose a part of their body and all that stuff, too and their figure. I did really well. I go swimming, and it doesn't bother me. I sit in the hot tub - it's a fact of life. People do look at you, sometimes….

Sarah: I don't know if they realize it was breast cancer, because I wouldn't have realized that. I would have thought the man had some other surgery. You don't think breast cancer can happen to a man.

Joseph: I didn't know a man could get breast cancer. Even the guy where I got my biopsy, he was amazed at it too. He said "I've never seen that before in a man" so he took a picture of it. He was surprised to see how the nipple was.

Sarah: When it first happened to him, I worked at a medical office. When he went to the doctor, all of this was done within 4 days. I said "there's something wrong, this is too fast' (*laugh*) when he came home and just said he was going to a specialist. But it was still not dawning on me, and it didn't dawn on me. I went and let him go for the biopsy by himself, I didn't drive him, I went to work, not knowing a thing. Not until the day our family doctor told him the results. I was sitting there and I was flabbergasted. I should know these things. But it was very very unusual.

Joseph: Nobody gave me a hard time about it. One of the women I work with had breast cancer before. When I was going for my biopsy she said "I'll see you Monday" and I said "no, I'll see you tomorrow…" which was Friday. I wondered what she was talking about. So I went for the biopsy. Afterwards the guy gives me a letter so I didn't have to go to work tomorrow. I asked "what's this for?" And he said, "well, you're not going to work tomorrow". THEN the pain started! During the biopsy the needle was in and out, like "zip zap, zip zap" . It was worse than taking your teeth out at the dentist, it was really painful. But anyway, I've been fine, I'm positive all the time. Why should I think negative about it? I had it, it's gone and why should I dwell about it? Life has to on. You just can't sit and look at 4 walls and feel sorry for yourself. Sarah knows how I am - up and about and away I go. We told my daughter and son about it. I told the people at work because I needed time off. I told them "I don't need a pat on the back, I'm OK".

Sarah: He was telling his sister on the phone that the doctor thought it was cancer. I told him "Don't you tell her that! You don't know that! Don't you go around telling people that!" but he had already been told it might be by the doctor, but he hadn't told me. And sure enough it was. But we all got over it, and it was good.

Joseph: It was an experience, but hopefully it doesn't happen again. Especially to this one! (*laugh, pats wife).* At work, well I think people and technology have changed; companies are pretty good about it. I went right back to work. People back at work would ask how I'm doing and I'd say "Here, here's how I'm doing" (*demonstrates lifting up shirt*). I showed everyone at work….and they'd all look at it and "OH my Lord!" With respect to the doctors and nurses, I think it depends on the individual himself and how serious the cancer is. I don't think mine was as serious as some people have it. There is support if you need it. I can call and they can help me out. I can't complain about how I was treated.

Sarah: The thing I found was that the doctor would check him out and give the pills for five years. Then you're out on your own - nobody checks you out. He gets his

mammogram, but is the family doctor supposed to check him? What happens after the five years? He had a blood clot 6 months after being on the medication, and he had no idea. He went to the hospital thinking he had a sore shoulder and nothing else. I phoned the cancer pharmacy about the medication, asking if there was anyone to follow-up. He was having problems. I don't know if you want to talk about this (*points to Joseph)* but sex problems, sex drive….

Joseph:…that's the pills that cause it…

Sarah: …and he says it's the pills, but I think it's the cancer. I've heard of other people who've had cancer who mentioned this to me.

Joseph: I asked my doctor about Viagra, and he looked it up and said no. With the blood clot my whole hand was puffed up; I had 2 little cuts and water was leaking out. I was at the hospital in this big lineup and I said "this is ridiculous" I mean, it's not a bee sting. Finally a nurse came along and found me a bed. The doctor ordered an X-ray and blood sample. They told me I had a blood clot, and it had moved to the neck, behind my ear.

Sarah: ….but nobody changed his medicine….

Joseph: There's a younger doctor there at the clinic now. And I've never had another blood clot, touch wood!

Sarah: He's got 2 years to go. Since they don't want to see him at the clinic, I figure he's OK.

Joseph: I don't really worry about the cancer coming back. You know, think positive and try to live a normal life - that's what it's all about. I mean, you can't just think about these things; you might as well live in a booth somewhere and die. I mean, a lot of people look for sympathy all the time or whatever. I don't get sympathy from my wife, but then I don't give her sympathy, either! (*both laugh heartily).* That's the way we are – we think positive all the time. I can see, if it had spread - that's a different story. Look at Peter Jennings; I was lucky it was only breast cancer. And we don't live life differently, not at all. Like at Sarah's Christmas party last year…..

Sarah: HO ho ho! (*laughing heartily)*

Joseph: Well, I had a little too much to drink. And the DJ playing the song said, "let's come and get sexy". I said,"well, you wanna get sexy???" I took my shirt off and started dancing - I enjoyed myself! (*laughs).* "Who is that crazy guy up there" *(indicating imaginary others watching*)…you know, that's what life's all about!!!
Sarah: He was saying, "Enjoy life! I'm not a female, but I've lost one of my boobs!" and everyone joked and laughed. They've got pictures! I'm not embarrassed, we had fun!

Joseph: It was a good time at that party…

Sarah: And I did give him a lecture the next day….just a little talk….

Joseph: Now tell the truth….

Sarah: It was the best Christmas party we ever had!!! (*laugh*) It had been pretty boring the first few years. We livened it up, all right! (*both laugh*)

Joseph: like I say, I go swimming and in the hot tub. People look at you differently for a little while, but I don't care. For other men, I'd suggest that they go find out more and we can talk. Think positive, don't think the opposite. I don't try and broadcast it because, I still smoke now and again. People would say "why are you smoking…you've got cancer!" I cut back some, but I've gotta cut back again. I've got COPD also so I really should! Cigarettes don't help. Too many people smoke at work. Some days are good days or bad days - sometimes I need a cigarette to just relax, you know? It's a powerful addiction. I've been smoking since I was 12 years old and it's pretty hard to kick the habit. I'm just like a junkie - you know, marijuana or speed or meth and all that stuff. But I don't smoke with people in the house, that's not fair.

Sarah: He did the relay for life and the walk for cancer as a survivor with our grandson. Everyone from my work saw that and started to cry. He walks in the relay every year, now.

Bert's Story

A retired couple have agreed to meet me in my office at the Cancer Center, as they were in the City visiting relatives. Both appear well, content and happy.

I first knew something was wrong when I had a rash. It was called Pagets disease and was there for quite awhile. Finally, I asked the doctor about it. He sent me to a dermatologist. He took a biopsy and there was nothing. But they must have suspected something because they had everybody in the clinic come and take a look (*laughs*). I went back to him and he sent me to the cancer clinic. They told me what it was. I had a mammogram, and my boobs are only this big! It didn't show anything. They said it could be one of the slow-growing cancers, but to be safe I should get it taken out. So I did, and everything's been fine since. And you can barely see the scar. The surgeon did the operation and did a beautiful job. At the cancer clinic, they all came to take a look, too (*laughs*). I guess it's very rare. I had it taken out, and there was cancer. I didn't need any chemo or radiation. I was very lucky and caught it very early. The rash started just after my annual physical, and it itched. I guess if it hadn't itched, I might not have bothered with it.

I had heard that men could get breast cancer. I know lots of women who have breast cancer, in fact my sister-in-law and my wife's sister in law, just the other day. She's got to have chemo and radiation - the whole schmozzle. The cancer clinic people were very up-front. I had a lady doctor - I can't remember her name. She was very up-front, but they were all good. I was just supposed to watch and make sure nothing happens to the other one. I had heard of it, but never dreamt that I would ever have it.

When I was diagnosed I told everybody I knew. Everybody, all our friends know. We told our kids when we were absolutely sure - no point of getting them in a state. Even the grandchildren, the ones that were old enough. Not one person gave me a hard time. Some people might have unkind remarks, but I think it would depend on the occupation, and who you work with. I was a teacher and they know about these things. And my kids are all educated, and most of our friends are ex-teachers or people we've known for years, professional people. But I can imagine if you're some guy who was a plumber or something. They make more money than teachers but might have a different perspective.

I never went without a shirt before because I sunburn very very quickly. I got a sunburn many years ago when I was a kid and it was sore and everything else. So I've never gone without a shirt. I don't swim, 'cause I hate swimming. So it's not an issue with me. I don't think I've had a problem with anybody. I know some men who have prostate cancer and they talk about it. I know and they know I know, so we can talk about these things. I guess I'm just lucky.

I've thought about the cancer coming back, but I'm almost 80 years old. So if it comes back, so what? There's not a great history of cancer in my family. I had a grandmother that died in 1926. I didn't know this before; I was talking to my cousin one day but it was bowel cancer. I had an aunt who had a cancer, but she was 96 when she died.

I have no idea why this happened to me - it just came out of the blue. I've had several operations, and I've had a stroke. Not a severe stroke - it didn't take me long to get mobile again. When I was first teaching, I had to get an X-ray every year, but eventually they decided to stop that. I haven't changed my lifestyle at all. I've been retired for just about 20 years. We do a lot of traveling, and we haven't stopped. Last year we went on a bus tour to Mexico, and I learned one thing - that I don't want to get up at 6 o'clock to get up on a bus for eight o'clock for 2 weeks! *(laughs)*

I think doctors and nurses should be honest, and they should let people know, straight-up. If they've been around for awhile, they know their patients and know how their patients would react. I know some people, you tell them something and they go straight up. They don't understand it, but you still have to be honest with them. These cancers that just go, boom, you get it and you've really got it. The less time spent fooling around is important.

Oscar's Story

A quiet man who invited me into his house in an established neighborhood in the City. He is alone. The interview was difficult and slow at the start, for his answers are short with lengthy pauses. As time goes on though, we are able to establish more of a conversation.

Well……when I was practising golf….I thought something felt funny…in my chest. So I changed my shirt…..I noticed the nipple had turned…that's when I first noticed something was wrong.

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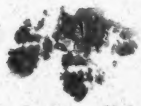

Well….I….I uh…didn't think too much about it for a day or two, and then as the days went on …I thought that maybe this was something serious….so yeah, 5 or 6 days later I phoned. I got to see a doctor the next day. He said, 'yeah, you've got something there. I'll get you in to a specialist.'

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Then, ah……well, I couldn't get in to the specialist for three and a half weeks….that's kind of a long time. But I heard that if you phone them and ask if they have a cancellation, you can get in earlier. So I did that…….that's what happened. They phoned back and said 'next week'.

Then uh……..let's see. ……..yeah……..I went in to see him. And he said, 'yeah,' ….I could see there was a worried look on his face right away. I still didn't…..I don't know…….I didn't think……..he said, 'it'll be awhile before you can get in, hospitals are busy'. And I thought here I go again, a long wait. But before I got to the waiting room, there was a cancellation at the hospital. Probably 4 or 5 days from then…..so…..

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So I got in the hospital and was operated on……..I came out of the anaesthetic and he told me it was malignant……

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Anyway, that's the whole story right there.

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Oh yeah……..like…….well, you know after a couple of days I had to keep going back to see the surgeon…….he kept putting a needle in to drain here……and uh…….one day I went back and he said "I have good news for you….there's nothing in the lymph

nodes". So that was great. He said I should still go to the cancer clinic. I kind of wondered why I should……

But I went……..I went…..they went over what I had…….you know, the possibility that there could still be cancer in the chest wall or……so on and so forth……so I mean, I went back a month later, then a couple of months later and maybe six months after that,……..then kind of on a yearly basis for awhile. I never had any chemo or radiation……
I'm very fortunate……

I do remember I looked up a lot of stuff on my own……..as a matter of fact, I knew more than the doctor did. I went to a bookstore……but as far as the cancer clinic itself, I can't remember if they gave me anything.

They recommended tamoxifen …I took that for ……years. Didn't seem to bother me. Anyway, that's the whole story…..and it's……fourteen and a half years ago…….

Well, I was looked after pretty good……..I know when I used to go for my checkups, I was really …….you know, there are those little rooms……..I was sure glad when I was called from the main waiting room into the little room……..so I booked the first appointment in the morning so that I'd be there before anyone else came in……I didn't want to sit around waiting……so if they could get me in without me waiting around out there……..

Before this all happened, ……my dad. ……..I didn't know……I knew he died of cancer, but I didn't know 'til later that he had …….something to do with breast cancer. …….so it shows you, it's something genetic there…….I never have genetic testing to my knowledge.

I have 2 brothers, older…….yeah. Well, they've got their health problems. Since I had this…..a couple of years later, a cousin of mine got it. She's fine now……she lives in the States……..I have other cousins with other forms of cancer, but not this……my dad's…….both my dad's sisters died of breast cancer…… I had heard of it…..but I still denied it, really, until the time I was told. Men just don't get it.

I told……well, my wife……and, um……then I think I had to tell somebody at work, 'cause I had to be away from work……then,……..that's about it, I think. A few months later, I let my brothers know……and, that's about it……..I tried to keep it …….tried to keep it under the rug……well, it seemed……..it seemed strange……..and I still do think today that……I don't talk about it……
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To this day, I just, um…….I know other people know about it, because other people have told them, but they don't say anything……I'm glad of that. But I never know, when I'm talking to somebody……..I'm thinking "I wonder if they know?"……But,…..I guess, if they do or don't it doesn't matter……..…fourteen years later……..yeah, ……..I keep it under my hat……..I have no desire to talk to anyone…..ever……..about it. If some guy knew I had it, and he had the same symptoms…..then I'd get him help, somehow. But just general conversation, no.

I don't think I've changed my life….I don't think so. Probably more conscious of ……..eating better…….yeah……..no, there's nothing……..nothing really different in everyday life……..I don't think I'm being much help here! (*laugh*). ……I didn't see any reason why I shouldn't take part….maybe I could help somebody….maybe even yourself with your thesis….get through university….I really don't have anything else to say.

I didn't want to do this…….my wife sort of said, 'yeah, you should do it', so I did it. And it's almost like getting something off your mind, eh? I guess one of the things that concerned me…..the form said 2 or 3 sessions ……I didn't want to do that, but when you told me on the phone it would be only one session, it was OK …...

Oscar's Story

I am at the home of an older gentleman who has been living with his son since his wife's death. His home in the City is older, but has been carefully maintained over the years. The living room wall is covered with framed photos of grandchildren at various ages.

When I first found out I had cancer, in my breast, it was discovered so quick – like. The first time I noticed something I was washing the car, I was cleaning, the roof. I felt something like a kind of prick in my chest. I jumped back and rubbed it, but didn't see anything when I checked. I thought "there must have been something there". But I didn't pay any attention to it, so about 3 weeks later I was putting an extension on my carport. My wife was working with me out there, and I was up between the rafters. When I got finished what I was doing up there, I turned like this (*turns upper body, looking down to ground)* to come down, and God, did it hurt!! It was an awful pain! I came down, and my wife asked if it still hurt. It really did, and she thought I'd better go to the doctor. We took a look at it, and. And the nipple on my breast was turned right in, like that (*twists wrist/hand).*

So, I went to see the doctor the next morning, and right away as soon as he looked at it he phoned the surgeon. I went down to see him and he wanted to perform a biopsy. I went into the hospital where they did the biopsy on the weekend. I had to go back in on Monday to get the breast out - that was in 1985.

I think it was in 1990 when I developed cancer in the bone here (*indicates sternum*).I've still got a lump on it but they did radiation and it cleared up. Later on, I got a terrible pain, just below my shoulder blades, closer to my spine. It was terrible, it just knocked the wind out of me. My doctor thought it could be cancerous, so they did an MRI to get a real close view of it. It turned out I have 2 spurs that are quite prominent, and that's what was giving me all the problems.

So far I've been clear of the cancer - I'm very fortunate with that. But my mother died of ovarian cancer; she was quite young when she died, only 57 I think. My father was 20 years older than my mother. He died in 1941 - he was 71 when he passed away. He had no cancer, but had a stroke when he was 49, and he was crippled. His left arm just hung and his left leg used to drag. I never knew my father when he wasn't crippled; my mother was always ill too, in and out of the hospital. One time, they took a 12 pound tumor out of her from somewhere - at the time we were just kids, eh? That's what she finally died of…ovarian cancer. It's gotta be in our family - my eldest son, even before I had that in my breast, he developed cancer in one of his testicles and had that removed. After I had this done, my eldest daughter had a breast removed with cancer, and *her daughter* had *both* removed with cancer. She was in worse shape than any of us, but she's done pretty good. She's had chemo and radiation is fine, except she's quite conscious that she's flat-chested. But what's bad with her is she's also got bad diabetes, both my oldest daughter and oldest son. Apparently, I'm on the borderline for diabetes, but I'm ok if I watch my diet. About 2 weeks ago they took a blood test and it was 8.9 and that's pretty good.

But with the breast cancer, the only trouble I had was that it kept swelling up, and the surgeon kept drawing liquid out. That went on for a couple of weeks or so you know, and it was still building up quite a bit. So I had to go back to the operating room, and somewhere in there was a sac - my body had built a sac and it kept filling up. He'd drain it, and it kept right on filling up. So once he got that out - I don't know what they did, but I never had any problems since. I've never had any bad effects, no side effects or anything, except when it got in that bone there, he was quite concerned. But after the MRI everything was fine.

When the doctor told me it was cancer, it was another thing, like I've had my gallbladder out, I've had my appendix out, and I've had different things like that. I don't know, I just took it in stride. But when it hit me there (*points to sternum*) then, I started to worry, because I thought now it's starting to spread and that can get damn dangerous. My brother- in-law, well he's gone now, but he phoned his brother last week, 'cause he developed a tumor in his brain affecting his optic nerve and he's totally blind in one eye already. He's in bad shape and his cancer has spread to his bones so he's had quite a time.

My wife passed away. She was ill for 17 years or so, with back problems and problems with her legs and eventually her kidneys quit working. I took her into the hospital one Monday morning and Wednesday night about 6:30 she was gone, but I've been fortunate.

I went to the cancer clinic after the surgery, that was a long time ago - 1985. I attended the cancer clinic every three months, I think it was, then once a year. Then when I developed this in my chest, well then I got radiation and I went quite frequent, then until this spring they didn't give me a future appointment but for me to get in touch if I had any concerns.

The only thing they did at the cancer clinic was to give me mammograms. I had a bone scan and X-rays, every part of me. But otherwise they were surprised that I had it. They all said, "we don't get too many men that get breast cancer"…I said, "well, my name is (*androgynous name).* When I was born they weren't too sure which I was, so they gave me that name." We laughed about that! They kept a close eye on me, they treated me pretty good. Any doctor I went to see in regards to cancer, said "do you smoke, do you drink?" I said, no I used to drink a little, but I haven't drunk for 40 years…

Cancer, I think it was in the family. I mentioned my son and daughter - I really think it was genetic. I know my father never had it, but my mother had ovarian cancer, and I think her mother had some kind of cancer, not too serious but some kind of trouble in that way. But I think it had to be genetic 'cause I didn't do anything to bring it on. A lot of people have cancer of the lung or throat brought on by smoking and drinking. My daughter and her husband have never smoked, it has to be genetic there. The same thing with diabetes, it goes way back to my grandmother on my mother's side.

As far as my breast was concerned, after the nipple turned in, they cleaned it right out. It was just as if I went in and had my tonsils out, or my appendix or gallbladder. This here was no more than having tonsils out. It didn't bother me a bit, except the breastbone. I

know a lot of people who had cancer that went into the bones and things went bad - I've been very very fortunate.

Once in awhile, if I had my shirt off, someone would go, "hey, what's going on?" they thought I'd had an accident or something. I'd say "no, I had cancer and they removed it". But no, other than that, it didn't bother me. When I went to the clinic for checkups, you'd look down this side and that side and you'd see all these big groups of women. Here I am sitting with a flat chest - other than that it didn't bother me. Every so often one of the women would look over at me and smile and wonder what I was doing there. I'd say "yeah, somebody took my breast away, it was cancer". But really, it didn't bother me at all, not a bit. And even going to the beach, it didn't bother me that it was sliced there because it could have been anything.

The doctors and nurses took care of me so quickly and seemed to know what they were doing. I thought that for a woman it's much more difficult, because a man doesn't have that tissue. I don't think it's such a big deal for a man if it's caught in time. If I hadn't caught that and it had spread more, it would be a different story. It's close to everything else and you never know where it might go. But the minute I walked into the doctor's office, he got on the phone and that was it. On the weekend I had the biopsy and on Monday I had the surgery! You can't get better than that. Other men might get it deeper so it's beyond repair before they notice, but mine surfaced right away. I'm very very fortunate. Neither my wife or I ever thought about cancer, we thought I'd hurt my chest working on the house. At the time my wife was having more problems than I was. There were times we waited a long time for tests and other things. Otherwise we really got good care, we've had really good doctors.

I haven't really changed things since the breast cancer. One time I was very depressed. I was to the point I couldn't talk to anybody, I didn't want to see anybody and if I did talk to somebody I'd be crying. When I got into the hospital I couldn't even tell them what my name was or anything, all I did was cry. So, I went to the nuthouse - the psychiatric ward, I guess you call it. They finally had to treat me with electric shocks. Way back in the 70's I had a bad bout. First of all, the psychiatrist put me on valium, and I thought that was terrific! One valium and I was in heaven, it just boosted me right up. Once I got off of that, down I went again - like they say, for every high, there's a low and boy, it was really low after that. He decided to treat me with electric shock. Back then, it was a lot different than they do it today. They just give you a little pill to calm you down a bit. There's 5 or 6 of you all lined up along the wall and the room's right there where they haul the person in. First you get up on this stretcher and they strap you in. Then they wheel you into that room. Some people, I guess, make a lot of noise when they're receiving the shock and that is pretty scary. There was one poor old lady there, she was like this *(demonstrates cowering posture)* and she kept saying "Oh Oh Oh" over and over. Just about drove me nuttier than I was! So, afterwards you had such a terrible headache. You'd come out of there and couldn't see properly because you had such a headache. Then the ward, there was a whole bunch of us, at least 10 beds in there. Well, I had 2 treatments and after the headache from the second one was over, I jumped out of bed, got dressed and I was walking out the door. A nurse came along and asked where I

was going - I said I was going home. She told me I'd better wait to see the doctor. When he came along and asked where I thought I was going, I said I was going home. When he said he wasn't finished with me, I said, "Yes you are". He told me never to come back and see him. And the thing was, I was fine. Until after I had the breast cancer - I guess maybe the cancer did hit me somehow. I guess it was after that, just shortly after that, when I got so depressed. As far as I had been concerned, I just shrugged it off. But subconsciously, it must have been affecting me, although I didn't think it was. With my wife was so ill, and I had other things on my mind - that's what I thought.

Outwardly, the only time it really got to me was when it got into my breastbone, there. I think I had 17 treatments when I was in the psychiatric hospital. Oh man, I tell you, there's where I was afraid, oh God. You have to sign a release form and everything else so if it kills you it's not their fault. The psychiatrist doctor, he says "one in a hundred thousand, it does happen" and I thought, you sure as hell helping me, aren't you? (*laughs*) There's where I was scared, I tell you. I put on a big front, but I wasn't brave, I tell you. OH god, you go out there and you're waiting. This way they take you into the room and you wait. You're not right there watching everything, but you know what goes on. And when you get there, they give you an anaesthetic and actually, it's not the treatment that some people die from, it's the anaesthetic. They just touch you with the needle, and you're gone, eh? Oh yeah, it's real fast. You're talking and then (*snaps fingers*) you're gone. I joked about it, but it scared the hell out of me. And you get a headache after; once your headache is over, you're feeling a little better. But I had 17 of those damn things; I think it was the second last one I had a heart attack, just a slight one. They rushed me back - apparently there was something they can inject you with in such time - it really works. My stomach was all black and blue from the injections, but then, I was only there, maybe 3 days then I was back in the psychiatric hospital, walking around. The following week, he sent me down on the treadmill, for a stress test - I did OK. The second time I went it was a little harder. But I got through it OK, and here I am!

Well, I've had problems, lately with losing my balance and dizziness. I attend a program, it's kind of a rehabilitation program where we do exercises, but mostly socialization with other people. It's been going on pretty good. One day I showed up there - I just got off the elevator and started walking down the hallway. I walked in and the nurse said "What's the matter?" I said, I don't know, I keep losing my balance. They took me into the office and took my blood pressure, and it was way down - 90 over 60 or some damn thing, So they put me in a wheelchair and wheeled me out. They laid me down with my feet up in the air, and the nurse made me an appointment with my family doctor. She drove me to the doctor, and she waited there with me, then she drove me home! You can't get any better service than that! It was just tremendous, you know? And then, two weeks ago I had another bad spell like that. I'm on some heart medication, and some of the medication I'm on will cause lightheadedness, you know? But my doctor says if he takes me off it I'll have angina attacks again. I don't know what to do. I figure it doesn't bother me too much, I just have to be careful. Like, if I stand up all of a sudden, I'll just go forward. So far, slowly I'm getting back on my feet again. My son here - he's like an old mother hen (*laughs*). He won't let me do this, he won't let me do that. If I want to go downstairs, he's "oh no no, you stay up here, I'll get it." And then, outside, he won't let

me bend over. I have a garden back there, a nice garden and I like working there; I like to get right down there, but I was having trouble also with my knees. I lost all the strength out of my knees for some reason, and I love getting down on my hands and knees, especially if I'm working in the garden, you know? Bare hands, I don't like wearing gloves. I get down there and work, and then I can't get up. One day, I had to crawl over to the fence and haul myself up.

Anyway, my cousin came over one day and she had this contraption that looked like a bench but had like handles. It was to kneel on, and then that way you could push yourself up. But then, I'd use it then I'd forget about it. Another problem I was having was if I bent over to reach something, I used to fall flat on my face. I had no control, I couldn't do anything. In fact, I have a raspberry patch there, too. You know how sometimes you're looking through and you see a nice big one? Well I reached over like this and down I went! I just laughed about it, I mean, what can I do? I'm not going to cry about it. If I fall and break something, well so I broke it. I want to live life as full as I can - I enjoy it. I like kidding around, I like joking. At the program there they're getting a little tired of me 'cause I'm always pulling some kind of stunt, but they're all good sports, those girls there!

There's no advice that I can give really, because some men are quite reluctant about it and I'm not. Like I said, it was like having my tonsils out - if it's bad, take it out. I think it would bother me a lot more like if I had to amputate a leg or something....you know?

Mitch's Story

An older gentleman with a wide smiling face greets me at his door. We are at his condominium home in the City. It is a warm summer day, with the sounds of traffic and children shouting coming from outdoors. In another room, a woman's voice can be heard, singing opera music in French.

I felt a lump, you know, while washing. I had broken my back, on the 19th of March the year before. So I was just washing up as best I could and found the lump while washing. There was no pain, just that thing there. I suppose I was surprised in a way, but I was more concerned that it would generate into a big issue. As it turned out it was gotten rid of at the right time in the beginning. So one day while I was at the doctor's office I talked to him about it. He said, "well, we'd better send you to the clinic". So he sent me to the clinic on 109th Street and they took what they call a biopsy. Anyway, the results came back that yes, it was a cancerous lump. So my doctor made arrangements with the surgeon. It didn't take very long. I went to the surgeon's office and on the 26th of January and they wheeled me in to the preparation room and did some tests, asked questions and stuff like that. They had a cancellation and asked me if I was ready to go, I said, "get it over with". As I was waking up I could hear a woman saying, "it's twenty-to-two and the operation was a success". When she said the operation was a success, it reminded me of when I was a technician. One of the things we'd say was "the operation was a success but the patient died anyway" (*laughs*). So here I'm laying there and waiting for someone to say the patient died - no one did! (*laughs*) Then they took me down to the wake-up room. I phoned my daughter - she had been planning to pick me up from the hospital. I told her the nurses were walking around and not overly worried, things were looking up. They were all talking in positive terms. So anyway that night, the old nurse said I'd be going home tomorrow. The next morning she came and got me.

The next two weeks I was on home care or community care services, with the nurses coming and checking the little bottle of blood and the dressings. They did a real good job with me, no question about that. They were real nice. Everybody around me knew about it. I didn't hide it from anybody. I can't say that I got big support, because I didn't ask for it.

I don't worry about it coming back. According to the letter from the clinic, I'm all clear. There's no indication of remnants or anything. They checked the whole thing out and they said that it was clean. It still feels funny, you know. It was the 26th of January, well a year and a half now. I went to the cancer clinic and saw the Oncologist. She had them put some bug juice in my veins and watched it on the graph - seems that it worked. That's what the surgeon told me, too. When I went to see him he said, "wow, I did a hell of a job on you," when he looked at the gap on my chest. I said, "it's OK, it's like a pothole, it'll fill up". The only other thing I notice is maybe a little pain with moving the shoulder, but I don't know if it's from that. I sleep on my right side all the time. If I've got pains, I'll take a tylenol 3 tablet before bedtime. I take my Arimidex at suppertime. Sometimes I rub the shoulder with rubbing alcohol or absorbine Jr sometimes and that helps.

I'm not sure why I got it, I don't know what it could be. I used to do a lot of weightlifting and exercising in the military. Maybe it started out with muscle strain or something, I don't know. I remember I'd been spraying the trees in the past and used malathion, which is condemned. So I don't know.

Well, the doctor there at the Cancer Clinic, I thought she was OK. She just told me what to do, and I did it, she's the doctor. When I saw her the first time she reminded me of an old army dentist when I was in the military. I was in the air force and one of my corporals went to get a tooth filled up. The doctor told him to sit down there. When the corporal asked if he wasn't going to freeze the tooth, the doctor told him he was late for his appointment. So when I saw her, I hoped she wasn't from that same school. But I never had any problems.

Cancer is cancer, what the hell? Like I say, I'm an old technician and so, you got a broken piece and you take the broken piece out and replace it with a good piece. They gave me a whole bunch of stuff to read. I just read the stuff to familiarize myself, I never really worried. I heal quickly and never really had anything that caused me any problems. I used to work with varsol and diesel fuel, cleaning up stuff and it never bothered me. I'm a strong believer in using diesel fuel for cleaning up greasy material or equipment, like car parts and whatnot. I just used to take a paintbrush and brush it with that, then take a steel brush and diesel fuel would do a marvel. I don't think diesel fuel would ever cause me any problems. I have a friend who has sore bones or arthritis and he always sprays himself with WD-40. It's the alcohol in WD-40 that penetrates. His wife told me that when he dies she's going to bury him with a can of WD-40 in the coffin.

The material from the clinic was quite comprehensive. There's a lot of stuff in there that more than covers things. Maybe I was a mild case and didn't need a lot of details. After the surgery and finding out that it was all gone, the rest of it was just like any other surgery, like having a tooth pulled, you know? Leave it alone, stop the bleeding and it will heal up.

I don't think it would have been helpful to talk to another man. I don't think so, I was doing well. I mean, the nurse was here and I was talking to her. She was joyful and made me feel good, same as the nurses who came in and changed the dressing.

If another guy I knew found a lump, I'd tell him to hurry up and get it removed before it's too late, you know? It's not going to do any good to wait. I thought that could be a problem, by not being painful and just hiding in there and waiting to grow up I might not have found it.

Lionel's Story

This gentleman had retired and moved to another province. As his mail was forwarded to his new address, he received the invitation letter and consent form then contacted me to participate. This interview was conducted by telephone; our audio-visual expert on staff was able to set up an audio-tape of the telephone conversation.

Sometime in 1989 or 1990, my left breast would swell up once in awhile and turn really red. A day or two later it would disappear and go back to normal. Every so often I'd mention it to a doctor, but it would be normal at the time he'd look at it. It would swell up like a young girls' breast when it's just growing and be a reddish-pink color. At the time we owned a hardware store; when we unloaded the truck and the box of the truck was at the height of my chest. So I blamed it on that, maybe getting hit so often. I mentioned it to the doctor a few times. I was taking medicine for blood pressure, so I saw the doctor often to get replacement pills.

When it really came out was in February of 1991. I went in for surgery for my gallbladder. While I was in the bed the anesthesiologist was putting the needle in my arm. I mentioned it to the surgeon - he pinched it a little and dark blood came out. He said, "you're not leaving here until I've checked this out." They took X-rays and blood tests before I got out of the hospital. In March I had surgery on my left breast and they removed it. A few days later, my right breast swelled up. My doctor looked at it and said, "Hmmmm, maybe we should just take that one, too". I said, "well go for it, I don't need those things anyway."
So they operated and took the right breast, too. In between that they took lymph nodes from the left armpit. The left breast did prove positive, so that's why they went ahead with the right breast. They didn't find any cancer in that one, though.

So the radiation was just on the left side. They made me a plastic vest there to take my treatments. And that did it, I guess. I did have a bit of a reaction. The last day of my last radiation my granddaughter got married. I went to the town where she was getting married and it was a real hot day. That day I sweated so much from the heat when I got back home that night, my whole breast turned into a big scab, like a radiation burn. That was the only problem I encountered, which was my own doing. I went back to the clinic for regular appointments for a few years, then they told me I didn't have to go back unless I thought there was a problem. So I've never been back since.

The only thing I have to say, when people go to a doctor and say they have a problem, it should be checked out. With me, it was disregarded completely. It was just a fluke that I had another operation and we had to wait for the anesthesiologist. It was at least a year or year and a half from when I first noticed swelling. Doctors should look into things like that. Why would I imagine that? That's the only thing I'm not happy about.

When I was diagnosed I told my three children. I also had a staff of about eleven girls working for me and they were running my business while I wasn't there and in the hospital. I could be reached by phone during treatment - I was very fortunate for that.

I was single at the time, my second wife had passed away in 1989. But I'm remarried again. I came back and married a girl I went to school with.

I had been to the Cancer Clinic many many times, because my second wife had died of cancer. I was in there often for checkups and spent a lot of time there waiting for her and seeing how busy they were. I knew what the staff had to put up with, and it wasn't all rosy. I considered myself lucky. I wasn't concerned, probably because of my prior experience. My wife had surgery, and lived for ten years after. The cancer seemed to be gone, but then came back. She was apparently filled with it and there were too many little globules to remove. She died of it in the hospital.

I don't think about the breast cancer coming back - I don't have any breasts! (*laughs).* But it could come back somewhere else in my body. I guess that's everyday life, for everybody. I don't think of it, really. It didn't scare me when I had it. I guess I've seen enough sickness. My first wife had tuberculosis and was in a sanatorium, she was sick for years. I was used to it. What else can you do? With the big blister I had on my chest after the radiation, I kept up with the sponge baths as I was instructed until the scab came off. It was pretty thick. But I had experience with that before. Quite a few years before I had my left hand blown off in an oil well accident. They put the hand back together - the four fingers were broken and the thumb was blown right off. When it finally healed, it was the same thing. I had a real thick scab over the entire thing that came off all in one piece and I had a perfect hand underneath there! So, those are experiences that helped me, I guess.

I don't know why I got breast cancer but I'm glad it was there, and not other places. Like people with brain cancer or tongue cancer - in funny places where it disfigures you. This doesn't even show. I don't feel differently about how I look - I'm not ashamed of it, I'm not afraid of it, and I'm lucky. I remarried after that, and I feel I'm still attractive, Things like this happen to you, it's not your fault. Not like people who disfigure themselves with rings and tattoos - why they do that? Putting rings in their nose, and side of their eyes and bellybutton.

I don't think I've lived any differently since. I kept on working until I was 65 and passed the business on to my children. I still keep in touch. I don't think I'm any different than I was before.

For other men all I can say is if they notice anything abnormal in their bodies, they should have it checked. Some doctors don't carry on with it. They're too busy or want the almighty dollar. I have no complaints and consider myself fortunate.

Victor's Story

Victor and Maxine are a middle aged couple living in a large Town in the southern part of the province. Their home and lawn are well-groomed, and both appear youthful, fit and healthy.

Victor: My wife is a nurse and at some point she noticed, while I was lying down on the bed that there was a crust on the nipple, and sure enough there was a lump, too. A small lump. So I went to my doctor, who put me in touch with a surgeon. He said it was not likely cancer, but it does happen to men. It's more likely something else, but we'd remove it. So we had the surgery in the morning; they went underneath the nipple, cut a flap and took the stuff out, then put things back. I was back at work in the afternoon.

About a week later, he phoned and said it was cancerous, that it was "in-situ", encapsulated, kind of like a cherry, and the stone was the cancer with the cherry being the flesh. They took out, but he'd have to make a report to the Cancer Board and that kind of thing. They told me to come in and they said they wanted to do a radical mastectomy. So with that they removed the nipple and the area around. They said afterward that there wasn't anything there so I was really clear. So that was OK.

We went back every six months or so; they had a schedule. After about the fifth year or so they said there's no point in just looking at me. I was told to just look and check myself; if there's any change or whatever, to come and see them. And that was all.

The experience in the Cancer Center was always very pleasant. The volunteers would come by asking if you'd like a cookie and tea and that kind of thing. And the staff were reasonably fast when you went in; you were out within an hour or so. You didn't spend a lot of time waiting, and all of that was fine.

We agreed that since my mom and dad were elderly, we wouldn't tell them. We told our sons and my wife's family, my sister and a few other people who were some distance away. For my mom and dad, if someone said "cancer" they would really freak out. My mom died in 1993 and my dad some time after that in 1996. We didn't mention it to too many people. One time we went camping and someone who was a nurse and noticed my chest. She asked if I'd had a pacemaker - I said "no, breast cancer". Now, nobody ever mentions it, even when we're out sunbathing or swimming or whatever. So it hasn't been an issue. I don't keep covered up specifically.

Maxine: you never really took your shirt off too much before, either.

Victor: I'm not that keen about getting skin cancer or whatever, so no I don't. If I go swimming or snorkeling I might wear a shirt, but that's for my back. Later, somebody picked up on it; I think it was the cancer magazine. They picked up on it and asked if they could do a story - I said "sure". I was in politics then, so they had their story. Then the two TV stations both did a show on men's breast cancer.

Maxine: Unfortunately, once the press got hold of it everybody knew, which I was not happy about.

Victor: I thought that well, if you might help somebody else, by knowing it happened to me. Forewarned is forearmed. I let my longtime campaign manager know, as we were coming up for election in June, my secretary knew. Whether or not people knew didn't bother me, after my parents died. I just didn't want them to worry. If it really was serious, they would find out.

Maxine: About support groups, I think it would have been different if you had needed some chemotherapy, but it was just that very short time when you were involved with it. It was over and done quickly.

Victor: Yes, that's right. I didn't have long periods of dreading something...

Maxine: ....or losing your hair. For women, that's the big thing, the support during the chemo. For men who do have chemo, they might be more likely to need support groups.

Victor: I don't know why I got breast cancer. Thinking back, when I was about 14 or 15, my breasts were really sore and sometimes fluid would leak out. I remember asking about it and my mother asked some people about it. Our children never experienced that.

Maxine: We talked to our kids about being sure if they had anything wrong that they get checked out quickly.

Victor: I did work on my uncle's farm, but don't remember being exposed to chemicals. I worked in the oilfield, but not a rig worker. I drove pumps and other equipment around. Mostly it was driving and hauling things. I wasn't exposed to the crude tanks, cleaning them out or anything like that.

Maxine: The only reason we noticed it was because it started to bleed. There was a spot of blood on his shirt a couple of times. We thought maybe the shirt was rough or something. After about the 3rd time or so, we noticed the lump. From the start to finish, it was only about two months or so. How long ago was it?

Victor: December of 1992. I didn't have any clue it might be cancer...

Maxine: Right away, when I saw it was bleeding I thought it might be cancer but I didn't say it to you. There was no point in worrying about it until we found out for sure. But I wasn't particularly surprised. I was happy to know it was encapsulated, almost like a cyst. I don't know how long that bump had been there before we noticed it. If it hadn't started to bleed it might still be there! You didn't examine yourself.

Victor: If I knew of another man who was diagnosed, I'd tell him to go and see a doctor! I could tell him "here's what happened to me". You know how sometimes when somebody had cancer and the condition is terminal, you can have a hard time talking to

them. Well, I don't feel I have as hard a time talking to them because I've had it. Obviously not as serious as they're experiencing, but it gives you something to talk about, and in a lighter way.

I stopped smoking in 1969 when I got a contract in Africa and thought I won't be able to get cigars there! So I quit! Otherwise, I don't think I've changed, not for the cancer. I've subsequently had a blockage in a blood vessel going to my heart and I've changed my eating; I drink more water, I have high fiber stuff like All-bran. I also now have an exercise bike where I can set the heart rate and programs. I did that for the first year or two, but now I just ride and increase the intensity. I walk while I'm golfing. But any changes I've done were primarily due to the cholesterol. It's checked at least once a year, I abide by the health guidelines and that stuff. Now my HDL and LDL are in the right range - I dropped my prevacol down to 20 units from 40 units. I eat ground flax. We were on a cruise for 16 weeks – I took my flax and the grinder. I love fish; when we're on holidays we eat lots of fish and we eat it during the week at home.

When I was given information at the cancer center, we had a laugh the time I was given a sheet telling me how to look up my bra and that kind of thing. I mean, that's understandable - for women that's an important issue. But they just didn't have anything for men. I suppose it's so uncommon I guess they wouldn't do something specifically for them, but it seems to me that if it's on the increase it might be helpful for men to have similar information.

Maxine: I think that it would be important for education or self-examination or awareness for men. Because I was a nurse I knew that men could get breast cancer but there's lots of people who don't know that. I think that educating men in some way that they should be on the lookout - just like women are and checking. That any suspicious thing or discharge should be checked. I don't know how you get that specific information out. I'm sure men don't examine their breasts. With prostate cancer, because of awareness men will go and have their PSA done and that kind of thing, so they've succeeded in that awareness. It seems like you hear more about prostate cancer now. I never heard any educational thing on TV about men's breast cancer. When they're advertising for women they should also put in a comment that 1% of all breast cancer patients are men. That's all they have to say. And make them aware, because there's lots of men who don't realize it can happen to them.

Victor: I don't know how breast cancer manifests itself in other people, or what the warning signs are. With my heart, I had indigestion quite a bit on a weekend of a funeral. After 3 or 4 days of ginger ale and rolaids I went to see my doctor. He said he had something for me *but* I had to go for an ECG. He gave me whatever it was, and that gave some relief. I went for the ECG and they said there's an anomaly. So off I went to the cardiologist; my doctor never hesitates to send you somewhere.

In about 1940, I was 2 years old when my mother came down with tuberculosis. My dad was checked and he subsequently came down with it, too. They both wound up in hospital in the west end of the City when I was a kid. In those days, they believed in

taking X-rays - for a long time I was getting four X-rays a year. I guess it was when I was teaching they said I didn't need to come and get an X-ray, otherwise it seemed I had to go every year.

Maxine: There might have been heavy doses of radiation at that time.

Victor: When I was a kid, I remember in the shoe department in the big department stores there was a machine you could put your foot in. You'd turn it on and then see your feet! The bones in your feet! You could put on a pair of shoes and your mother could see where your toes were and if they were cramped. I don't know when they quit that.

Maxine: There was an X-ray technician that I worked with here when we first came, and she's in terrible shape, you know, just lots and lots of health problems. I bet you it's from all the years of radiation she absorbed.

Victor: With respect to participating in this study, I did a masters degree 30 years ago, something called "comparative education". I was always interested in geography and education systems in other countries. If people don't answer questionnaires or participate in studies, how do you do the research? So, turning it around the other way, this is pay-back.

Garth's Story

An older gentleman greets me at the door of a large home in an established neighborhood of the City. We sit in the dining room and have coffee, where large framed university graduation photos of three children dominate the wall.

Well, I was traveling in Australia for a couple months. I was carrying things in my breast pocket and was irritated - when I got home I felt it and thought, "gee, that feels like a lump". I went and saw my family doctor right away. I saw him on a Monday - he put me in touch with a surgeon whose business is breast cancer - he's since retired too, of course. I saw him on Friday and had the operation on Monday.

It was very quick – there wasn't a wait at all. My family doctor had helped him at different times with operations. So from the time I first visited the doctor to the time I had the operation was a week. When I saw the surgeon, he said "I've see so many of these…I can tell you that you're probably going to have breast cancer". He said "we'll do the biopsy, if it's cancerous, we'll do the breast."

It was really quick. The recovery was very short, the physical part of it. I think the mental part also, simply because I'm a man. I think it would be hard for a lady to lose her breast, otherwise for me I can't say it was a terrible trauma. Real trauma is worrying about whether it's going to come back or whether they got it all or didn't get it all, that sort of thing. But they did remove the lymph nodes, and they were non-cancerous, so that was good.

I went to the cancer clinic for 10 years. I was on tamoxifen for 9 years. I started out at the cancer clinic with really short turnarounds. They extended to six months eventually and then the oncologist took me off the tamoxifen because of stories of being too long on it and causing problems and so on. So essentially that's what happened. I've been on nothing since. And that's been 16 years altogether. But I still do the testing - checking the other breast and underarms and all that. Hopefully it's gone.

My wife was there, of course and I told her. Well, she wasn't there when I first went to the doctor. I've told lots of people since. I don't have any problems talking about it. It doesn't make any difference from my standpoint, and maybe is educational from somebody else's. But you know I don't know another man who's had breast cancer. I know all kinds who've had prostate cancer, which I've also had.

There's been a number of things that make me appreciate being alive a lot more than I might have otherwise been. I had a very bad fall a year before the breast cancer off a collapsing roof and I was diagnosed a couple of years before that with diabetes and I've had heart attack since then. And then prostate cancer, too - I guess I'm pretty tough! *(laughs)* So each one of these things makes you appreciate each day more than probably the average person who's never had anything happen to them. And I think that probably the first real scare. Well, the diabetes wasn't such a big deal, but the breast cancer, definitely. Disease-wise, that's the one that makes you think, this could come back in a

year or six months or whatever. I think about it some, yeah. Like I say, I still check for any lumps or anything. But you know, as each year passes you get more complacent about it.

I don't know if there's advice you can give people, each person's different. I guess as an example, you can survive and I've done that for 16 years, and that's a positive, I guess. But how a person's going to feel themselves, I don't know. Like, I didn't have trauma as such. Sure, I was upset, bothered at the time but not in the real sense that it stayed with me. It would depend on the individual's reaction, I guess.

I've had the impression all along that all the write-ups and things are geared to women as opposed to men, although within that stuff, I remember the 1.5 or 2%, that number was someplace. And another thing I've never seen - you know, they have the walk for cancer and all that stuff. All the girls paddling and wearing pink and the ribbons and all that. But you know, I've never seen men participate in that. I don't know if that's a denial or why they don't participate. You never see anything that says, 'men, you can get breast cancer, too' so pay attention, that sort of thing, it's just not there.

With respect to support groups, I haven't even gone to a prostate one. They have them down at the prostate center. I guess if I had need of significant support, it would be there. It would be a chance to talk to them about what treatment they had and so on. But then, if there's only been ninety-some men in all of Alberta since 1970 I think it would be a pretty confined group. I'm not sure how effective that would be in the long-term. I think women tend to lean on one another more than men do, by nature, all the time, not just for breast cancer. Men tend to be isolated a lot more, choose to be isolated a lot more, I think.

I think health professionals could do a much better job of telling men they could have breast cancer. Every time they talk about women's breast cancer they could put an addendum - it could say "men, you can have it too", you know? I don't know, if I hadn't felt the lump myself and went in and checked on it, it could have been another 6 months until the next medical and whether that would have made a significant difference, who knows? But I think that it's as important for men to know they could have breast cancer, that they make sure they check and find out. I think certainly the health system could do a better job of telling people, because like I said, I had absolutely no idea about it. The fellow I talked to yesterday whose wife had had breast cancer didn't know men could get breast cancer. There's all kinds of people - nobody knows that it's even possible. I don't think they should take away at all what they're doing for the female part of the system because that's the big part, but they could certainly put a comment in any kind of publication. It certainly needs some improved awareness, I think.

Well, I know my perspective has changed overall, from since when I was busy and active in business compared to now. I relax more, I have time for a lot more things. I enjoy doing things that I never did before, and I'm very thankful that I'm still here. But as I said before, I can't equate that specifically to the breast cancer, it's part of it, I'm sure.

And I find all kinds. We have several friends whose female partners have had breast cancer and died. Every time that happens you become aware again of the vulnerability of it, and some of them who were originally diagnosed then a long period of nothing and then a recurrence. So, it's scary. You don't belittle that at all. I don't have any words of wisdom how to deal with it. In my case it was so fast and it was over, the breast was gone. Physically, I was feeling great within about 2 days. I think that if it had lasted longer, if I had worried or fretted about it for a longer period of time, waiting for an operation and all that it would have made a heck of a difference in how I would have needed to deal with it.

I have no idea why I might have had breast cancer. I talked to my doctor about it. I have to admit I've always been a bit overweight, it's a family trait. People in my family have always been troubled by trying to keep weight down. So I know that's one of the potential causes of it, but otherwise I have no idea.

I don't normally go without a shirt anyway, but if I go to the swimming pool I get in the hot tub with people or go to the beach, I take my shirt off. After I first had the operation the scar was very red. My doctor said that would last for six months or a year, but it lasted for 8 years probably, and quite red. Since then it's kind of disappeared. You can still see a small scar there, but it's not so obvious. I could see where if someone felt they had the perfect body and then it was scarred, they wouldn't want to be showing it off. Maybe because I had very bad acne as a youngster - living with that sure wasn't easy. You know, when you're coming into your teen years and you're getting hormones and thinking about the girls but worrying about the zits. You have to get over it sooner or later, cause you're stuck with it. And appearance isn't everything - maybe that made a difference, I don't know. And maybe somebody who is younger would feel different. You sure see the ads about people with perfect bodies.

Nick's Story

Nick and his wife live in a large Town in the northern part of the province. Theirs is a large older home in an established neighborhood.

Nick: I didn't realize it was there, there was a lump in my breast. They had to take the breast and all away. Apparently it had been there for a long time, but it hadn't bothered me. I had my surgery at the City, then the lymph nodes in the large Town nearby. I had no problems, it went over smooth.

I had no idea men could get breast cancer. You never know what you've got until they autopsy it. That night, they took the needle, and in the morning they operated on me. It was very fast.

Pearl: Well, he was in the hospital with his prosthesis, eh? He was getting an amputation, the first one didn't heal. It was two and a half years before it healed. They had to cut it off above the knee, and then it healed good. It took awhile, being that he's diabetic.

Nick: The nurse in the City hospital came in and she found it. She and another nurse came in and they were going over my body and finding things. They were very thorough - the more you find out about things, the better. They brought it to someone's attention, and I got it done the same time as the amputation.

I told my wife when it was all over, it happened the same day. My youngest son knew. He lives near the City and then our boys out here, and our daughter.

I sometimes think about it coming back, I also worry about if they got it all, you know? They didn't find any cancer in the lymph nodes, but....

I've told my friends I've had breast cancer. I've had three or four brothers pass away from cancer, and a sister - all different cancers, out of eleven of us. And I've escaped it now, for the last four years. My health is fair. I can still to a lot of things, if I put my mind to it. We've lived here for thirty years. I came in 1969 - construction and carpentry work. The town was just starting out.

I don't really have any suggestions, I can't complain. They had to cut a bit across the chest, then took the nipple and all. It didn't take very long. I'm glad they got it. I've had no after-effects but a bit of numbness. They said I didn't need to go to the cancer center after the surgery. I've been on tamoxifen tablets for four years now. I've had no side effects I've noticed.

I don't know why it happened to me. That's what I asked the doctor. I got a lot of bumps on my chest, playing ball. You never think of that, then all of a sudden it popped up.

Alex's Story

An older couple invited me into their home in an upscale neighborhood in the City. In their sitting room, we had tea. Numerous family photos are framed and arranged throughout the room.

Alex: I just found this lump in my left breast one day. I didn't think anything of it, and didn't say anything to my wife at the time. We went on a holiday first - that would have been in February or something like that. I went to see my doctor in the beginning of May, and he dispatched me to a surgeon for a biopsy. He said "well, that shouldn't be there. " Anyway, on the 30th of June, I found out it was cancer, quite abruptly, by the surgeon (*laughs*). I was in there by myself in his office. My wife had insisted on going, and I said, "what for?" We had just bought this house and took possession that day, so I said "just stay here and supervise," but she insisted on coming along. Anyways, so he said "do you want your wife in here?" then he proceeded to explain all the options. She was pretty upset. I'm probably in disbelief about it, or denial or whatever you want to call it. The surgery was 12 days later. It was OK going in, but it wasn't fun coming out! They ended up doing a radical mastectomy, took lymph nodes and thank god those came back negative. Since then I've been clear, My sons and I were going to do the walk this weekend, but I ended up breaking my shoulder a couple of months ago and I've been off work ever since.

My treatment was surgery and radiation. That's where I got my frozen shoulder, I think, from the positioning, But you know, if you're going to get cancer in Alberta it's as good an experience as you're going to get. Especially here in the City. I started having problems and they made sure I got in the lineup early for an MRI and a bone scan - they wanted to make sure there was nothing else going on. So it was a bad experience that wasn't really bad, you know what I mean? It was pretty traumatic my wife, I think. She can probably explain that better than me. I'm probably in denial or not facing up to it, but I seem to be OK now.

We told our sons that day, and then as a family we kept it to ourselves for a few days. Everybody was concerned and worried. I told the people at work right away - they were pretty good about it, overall. I was off work 14 months, and was back for 5 months and broke my shoulder. Maybe I should retire. With respect to living differently, I think I'm more aware about cancer, generally. I'm interested in what's going on, like the breast cancer walk this weekend.

Jean: And fitness and our diet. You walk just about every day, and we're babysitting our grandchildren.

Alex: At the Cancer Center, they offered you anything and everything, from help for your mind-set to the drugs you were taking and the medical care. The oncologists, the volunteers, they're all very nice. You never know what to expect, but it was really good.

If I could go back in time, maybe I'd do more checkups, more doctor visits especially with my family. I've got 2 sisters with breast cancer, one since I had mine, one died just in May. More preventive stuff. In the past, I'd go to the doctor only if I needed to - my attitude was "if it isn't broke, it doesn't need fixing" (*laugh*). But I don't hesitate now, and that's another thing that's new. I go to the doctor more quickly than I thought I'd ever do - I don't hesitate if I think there's a problem. Of course, with my shoulder, I got the results of another MRI last week, and it's looking better. Another thing I'd probably recommend is the exercises that they recommend - really work hard at those, that's probably one of the most important things. My arm probably wasn't in shape, even though my radiation didn't start until October. My arm wasn't in shape to take that. Just a minute and a half of being in this one position each day. I'd recommend that as a must. I had this arm in a sling for 3 weeks, and nothing but problems. I think you're afraid to really push it too hard at first, so you don't do it like you're supposed to. Maybe people aren't encouraged enough that it's OK to do it.

If someone I knew found a lump, early detection is probably the key. Get yourself checked out. I talked to all my brothers. The gene is in the family, and it's very possible they could get it. Looking after yourself is important. My younger sister likes to try natural stuff. That's what she was opting for, but then she did both the surgery and natural stuff. We kind of helped her "see the light" !

At my exercise class there was 14 women and myself - I was the last one in. The gal who was doing the class was not totally surprised. All the classes are geared towards women. I mean, that wasn't a bad thing. I've never been one to want support or counseling, it might be beneficial for someone else. As far as the cancer itself, I think I've coped alright, I guess I try to have a positive outlook on things. But with the frozen arm and everything, I didn't cope too well with that. I was on so many different painkillers, that didn't work. It hasn't been any fun. It's been depressing not to be able to do the finishing touches around here....painting the closets, yardwork, it was hard. Probably that's where the depression came in. And I know it sounds strange, since I said I was positive.

We went out to BC the week before and I thought about staying covered. The first day we were there it was pretty hot on the beach. I had a UV shirt but I don't really think about going without my shirt. My grandsons often ask to look at it, they're pretty open. It's amazing how intuitive they are. They know if you're hurting as young as they are - that's quite amazing. They do take your mind off things, they actually helped a lot.

George's Story

An older single gentleman in a tiny bachelor suite crowded with the furniture of illness; a walker and oxygen tank. Several trays of bubble-packed pills were scattered about on the cluttered table and countertop. He seemed pleased to have some company.

That was…..that was when? Must have been a couple of years ago, I think. I can't remember when it was. It was my day to see the doctor and she called me in. She was looking at me and says, 'what's that over there?'. And one of the nipples on my breast was turned inside out. No pain, nothing. I saw it for months, maybe longer than that, but it didn't bother me. There was no feeling to it. I didn't know what it was…it was just sitting there, a turned inside-out nipple. She said, 'I want to send you to the specialist.' So she made up an order and I had to go in. They sliced that nipple out of there, the whole thing….just sliced it out. The test they took on me showed there was some cancer, somewhere. So they didn't know what they were looking for. I said, watch it, I've got a pacemaker there. I have to watch for that, now. By evening, they had me sliced off. They figured there was some cancer, and that they caught it. I think they took some tissue from the armpit, too. There's a big hollow, now…..different from the other one. If things don't hurt, I don't worry about them.

I went to the Cancer Clinic, they called me in and sent me way down to someplace. They checked me out and chased me up and down the halls (*laughs*). They couldn't find any more cancer. It must have been a very small thing on the nipple. They caught that. My main problem right now is my right leg. It's short….since 1977 I've had four hip replacements. I'm 85 now…..(*brings out bubble pack of pills)* One of these pills is for the cancer, and that's what I take every day. They check me over each time they call me in, every six months. I hope this is the last one….

I had four sisters, now I have one. I have one son and a grandson, and that's all my family. In 2001…..the doctor told me then I had a problem in the heart…..how did that come up? They were always checking me, then they found something that didn't ring right with them. They put me through so many different tests; they would do one test, then couldn't find why they were hearing a noise. They checked all my arteries, and that one thing that kept making noise is still there….they can't find where it's at. Right now, I've got a pacemaker in there. They had me on the operating table, they took the heart out and put it in a dish and set me aside while they worked on the heart. When they put it back and woke me up, they said, 'well, you're here now' and I asked if I was alive then went back to sleep. I've had so many surgeries.

Well, there was five of us in the family. My niece was a nurse and she looked into these things, and she found that between the five of us children there were 2 without a touch of cancer. My oldest sister died of cancer, my next sister just passed away in 1990 - she had her breasts taken out. They had worked on the breasts, and she's gone now, too. The third one, she has no cancer on her, yet. The fourth sister, she died very young in the early 80's….she had cancer in the breast area and went into the bone - they couldn't take it out.

So she passed away. Four sisters and myself. And I'm now stuck with the cancer. And since they took my prostate out I'm good for nothing anymore.

Well, early in the '80's, shortly after ....who was it now? My wife was a very sick lady...she was struck down with Alzheimers. It sort of affected me, with high blood pressure and all the other pressures on me now. It bothered me. She died, not of cancer but.....what did she die of? Anyway, she passed away. She always said she was going to outlive me. She was from a good family of Irishmen.....what was I going to say, now?

From then, when I had high blood pressure, I got a lot of information out of Prevention magazine - they tell you everything. I don't eat fat, I only have eggs every once in awhile. I rarely use salt.

I had never heard of a man getting breast cancer. Men aren't supposed to have it. Maybe I was the first one to have it. When I had my first hip replacement, I was a mailman at the time. They had me in the hospital and did tests for two weeks.

The surgeon who did the breast surgery, she was very young. An older man checked me out but wasn't able to do the surgery. She worked on me, sewed me up and sent me home.

The Cancer Clinic, well, they call me every six months. I have been going up there every time they give me a call, I've taken the bus so far, and there's a bit of walking to do, but if the weather is not inclement, I could make it. But it's quite walk...the first time I walked a long ways because I didn't know how things worked. But I'm hoping this is the last time they call me. They told me I should be coming in, about six months ago. I know what they'll be wanting to look at. I've got this sleeve that needs looking at - it's about time to be coming off. I've had this - it's the second year now. The last time she checked me, she measured my arm and I think it's about time it was coming off, it's getting thin, now. Very thin. I'm skinny compared to what I used to be.

Ivan's Story

A middle aged fellow visiting the City on business agreed to come to be interviewed and chose my office as the venue.

I'm not very good at remembering dates. It must have been March, and I was washing myself and noticed a little lump on the side. I went to the local doctor and he said "that looks suspicious to me, you'd better get that checked out" so I came to the Cancer Clinic here, where they did a biopsy - which hurt like crazy. I was going back and forth to B.C. with work at the time, when I got a call from my son saying that the results were positive. So we made arrangements to go into the hospital and I had the operation. Now the operation was exactly 30 days from the time when I first noticed a lump. Some people complain that medical service is not very good in Alberta, but I didn't have a problem with it, I thought it was quite good. And I had the same doctor as my mother did! He did her operation 6 months prior to me. There was quite a few years difference in age, but we had the same operation. He did a very good job. My grandmother had breast cancer as well. My mother has some loose skin under her arm and a few things like that she's complaining about since her surgery, but I don't have any, it's as tight as can be! They told me to take it easy when I got home from the operation, but the first thing I did was crawl under the van and change the oil! *(laugh)* My mother said not to lift anything over 10 pounds, so I picked her up! *(laugh)*

After the surgery, I went to the cancer clinic for an interview with the doctors. I can't recall if that was before or after surgery. I know I came here for medication, because I was on tamoxifen for 5 years. You know, when I first noticed the lump it was about 1 cm, and by the time they got it out a month later it was 2.2 cm - it was growing! Dr Fraser thought I had it for years, but not if it was growing that quickly. Anyway, they got it all, but it's an interesting story.

I had heard that one teaspoon of sugar will stop your cancer-fighting antibodies for 5 hours, whether that's true or not I don't know. Anyway, there are 6 teaspoons of sugar in a glass of Coke - and I used to be a Coca-holic - I could drink up to 2 litres of coke a day. I figure my cancer-fighting antibodies never got off the ground! *(laugh)*

So maybe that's part of it, I don't know. The surgeon was quizzing me as to whether he might be able to find some sort of a cause. I couldn't think of anything that I had done that was different from anybody else, you know? Unless there's truth to the rumor that radiation sneaks out of the microwave or computer monitor or something like that, because I do spend a fair bit of time in front of the computer. I think it was hereditary.

There was no information given to me about male breast cancer! The only information I was told was that 40% of men who get it die from it. Probably, because they are not looking for it and they don't react fast enough is what I would guess. Other than that, I don't know the percentages of men who get it. I haven't seen another man - it makes you feel a little unusual.

When my son called me and said the biopsy was positive, I was shocked, but not devastated. I thought, well, my mother had just gone through the operation and she came through OK, so I thought I'd go through an operation, get it cut out and that would be the end of it. I was pretty sure I caught it early, so that the operation would be successful – I was optimistic. I wasn't heartbroken or devastated or anything like that. Since I was in B.C., I don't know what my son's and wife and son's reactions were at the time, I'm sure they were concerned.

I must have told some people at the time, because my cousin came to visit me in the hospital – she lived right nearby. But I was only there for about 24 hours with the surgery. I didn't keep it a secret, but I didn't refer to it as breast cancer, either! (*laugh*) I just said I had a lump on my chest. I don't know if this means anything or not, but I have probably only referred to it as breast cancer in one instance, that's it. In my experience, I've never heard men's breast cancer mentioned. I was quite surprised and shocked when I found out men get it - I just didn't think it happened! So, I felt a little strange, but I just dealt with it.

If I had the chance to speak to another man who'd had breast cancer, knowing me, I probably wouldn't! (*laugh*) I'm not much of a communicator, to be honest. I'm not a social creature, never have been. I would have read a brochure on men's breast cancer – I read what they gave me. I think it would be more helpful if it was common knowledge that it happened in both sexes. I don't think I would be quite as embarrassed about it. I know I don't go swimming. I used to a lot, but I've never gone swimming since the operation. Things like that. I make sure I've got my shirt on all the time.

I've changed my lifestyle a bit – I've cut back on sugar quite a bit and have given up soft drinks completely. I'm not a fanatic, in that I won't take anything without sugar but I've certainly cut down. Maybe moderation is better. If there's any truth to that sugar can affect your cancer-fighting mechanism, well, then I was fair game for it because I certainly had a lot. I'm not an exercise person, I never have been. I'm active, I get out and I'm busy all day. My wife has gone on an exercise program because in our shop we have a gym set up and an exercise room for the whole staff. And she's working out and has lost quite a bit of weight. She's in good shape and in fact she holds the record on the elliptical trainer! She's done one mile in 10 minutes or something at level 16! Even guys can't do that! (*laugh*) And I do 2/10 of a mile on level 4 or something and I've got sore legs! *(laugh)*
And I don't work as hard as I used to; I like to spend time in the garden and play with the grandchildren and spend time with the family. This year I didn't go fishing, but last year I did go fishing a few times. I don't know - I just kind of go at a slower pace. I enjoy my job, but I was kind of burnt out, I used to work excessively at it. It's nice not to push so hard.

With the tamoxifen, they explained possible side effects and there was a variety of them. The only one I remember was to watch for blood clots in your legs and things like that. I had no reactions at all, but I did notice that while I was on tamoxifen I bruised easily and

the marks stayed, kind of odd brown circles that don't change. Here, I'll show you (*lifts pantleg to show shin*) that's it. Otherwise, I didn't notice any side effects.

If I could suggest changes for doctors and nurses, I don't know. I have absolutely no complains about how I was treated, how I was looked after and cared for. Everything was explained to me really well and the cancer clinic provided the medication free of charge. I really can't complain at all about how I was treated. I can't think of anything that could have been done better. They did tell me that men did get breast cancer and that was reassuring to some extent, so maybe some written information would have been helpful. I think women are more social than men, so find support groups helpful. I was never one of those kind of guys, I had one male friend, one good friend when I was in grade 9. We were friends because we were the same. I'm not comfortable socializing with men, particularly. I grew up in a family where I had 3 sisters and no brothers, so I'm more comfortable with women - I really am. I don't know anything about sports, so I can't talk to men about hockey or football or things like that.

If a man I knew was diagnosed with breast cancer, well, I wouldn't really have advice. Nothing other than the obvious: to get the operation and get it taken care of. I don't consider myself to have emotional hang-ups or being bent out of shape or changed my personality or anything like that. You know, I might be self-conscious, but other than that - I was self-conscious before, anyways! (*laugh*) it certainly hasn't been a dark cloud hanging over my life or anything. I'm very very grateful for the medical treatment I did receive and for the fact that I have recovered and you know, I've gone on to experience life in these years. Being an grandfather with my grandkids….you know, I would have missed all that. I'm enjoying it!

Since I've had cancer I've noticed that I'm not as strong as I used to be. You could say it's because of the cancer, or because you're getting older, and that's quite possibly true. But it just seems that in that time frame, even though I've recovered I can't lift as heavy an object as I used to be able to. I just don't have the same strength at all and I notice that. When I'm working, if I'm hauling things I have to ask one of my son-in-laws or my son to lift something - in the old days I would have just done it. I don't have the same endurance, of course, I don't exercise either! *(laugh)*. I never exercised before, so it's not much difference. It seems to have sapped my strength. It could be that I'm five years older, too. Look at my father - I never used to be able to beat him at an arm wrestle, but I wouldn't try it now, because he'd probably have a heart attack*!(laugh*) but I probably could beat him now! He's not nearly as tough as he used to be!

I don't worry about the cancer coming back, I'm pretty sure it's gone. And from what I understand about tamoxifen, it's pretty well prevented any residual cancer cells in my body from regrouping. I've thought of it occasionally but I wouldn't say I worry about it. I consider myself a cancer survivor, going on with my life and nothing is unusual. Now I can't say that about my mother. Well, my grandmother had breast cancer first, then years later she had cancer in the pancreas and died, so now my mother is convinced that is going to happen to her. I have no such assumption, I don't think that's going to happen to me - I just don't. I don't know why that would have happened to my grandmother. They

lived in a small hamlet and had large gardens. Everyone ate all natural foods and were all very healthy. My mother is a real worrier. We used to tease her that if she wasn't worried about something she'd worry about not having something to worry about ! *(laugh)* I've had a laid-back attitude about this – I'm living my life fully with my health and my family. I'm blessed!

Edward's Story

An older gentleman invited me in to his apartment. He has a wide smile and jovial attitude, and we sat down at his dining table for our talk.

I can tell you my experience with it. The breast was sort of sore, but not really sore. And I thought "well, it's just something" and then the nipple became inverted. I was working with palettes and I hit a palette against there (*indicating chest)* and blood came out. Well, I knew it was time I had to have something done right away. So I went, and my doctor looked at me and he sent me for ultrasound, but it didn't prove anything. And I went to another hospital, and they finally took a biopsy. OH! It was the thing that hurt the most, taking a chunk out of my breast without any freezing! And they diagnosed it. It came back very soon from the Cancer Center, that it was cancerous. So once we found that out, they operated right away. I was very fortunate, from the stories I hear. As far as I was concerned, the health department treated me very good, except that I'm still waiting for a hip replacement for quite awhile (*laughs*). But they were going to operate right the next day after they found out it was cancerous. I asked if I could have a week to get things in a little bit of shape. So they went on with it, and it was quite an operation. They removed the whole breast completely and took the lymph nodes out. I went on the tamoxifen program for five years and everything seems to be very good.

I asked the doctor if there was something that caused it, would it have been an injury? He said, no he didn't figure so. And the doctor was a very very good doctor as far as I was concerned. He did a very good job. I took a month at the Cancer Center getting 21 shots of radiation. I think it was a very good idea, but it takes away your strength. And my strength never has really come back. But of course, you've got to take everything into consideration, you're getting older, too. So you might have lost your strength without the radiation (*laughs*). So, it went very very good, but it sure burns! I tell people I've had more sunshine than you guys if you lived in Africa all your life! (*laughs)* .

I'm a meatcutter by trade, for 38 years. At the time I was working part-time at a store and also taking bets on racehorses, so I never really missed very much work at all. I also worked while I was taking the radiation. I'd go back and forth, but it was the only thing I could do.

I never told anyone about me getting breast cancer. I think I told my boy - he lives in another City. My wife and I have been separated. I drove myself to and from the hospital. I'll put it this way: in my own mind I think I accepted that I had it, but didn't want to know it. That's foolish, very foolish, I should have it diagnosed sooner. And now that I've got prostate cancer, I said to the doctor, "do you think I should continue with the breast X-rays?" He asked "do you get any pains, do you have any lumps?" I said, "no". He said, "no, I don't think so." I figure he's a pretty good physician.

At the Cancer Center, they treated me great. Walking in the first day, the woman who was running the radiation machine, says "we got you now!" (*laughs*). I said, "yeah, you got me! But maybe not for long!" We joked about it, but it's not a joke, it could kill you.

But the better you can accept these things, it's better for the people who are working with you.

As far as things go, I found out more about things from Bill, who was giving me the radiation treatment than I did from anyone else. The radiation doctor was pretty reserved, didn't tell you much. But otherwise, I have nothing to add, except that anyone who's got it get a quick diagnosis and follow instructions. There's a lot of people who go for medical help, but don't follow instructions.

There are a lot of people who have cancer who like to talk about it, but I don't know, I never thought about it. Some people get pretty upset and I really didn't require anyone to speak to. I never even thought about it at the time. But if anyone did get it, I'd gladly speak to them, anytime or anywhere. If I could be any help. I'd tell them that a lot of people get something like this, and the worry is about as bad as the disease itself. They get quite upset. Naturally, none of us want to meet our maker, but it's inevitable.

I haven't worried about it coming back - even today, I still feel pretty good. I'm 72, but I actually feel pretty good. And I drank quite a lot of beer. Every doctor I went to, I did not hide that fact. But the one guy laughed. "how much do you drink" and I told him. He said "oh my God!" And I said, "well, should I drink whiskey?" and he said, "no, it's the same thing". And I asked, "will it hurt me?" He said, "no, but I'd wonder about your liver". I said, "no, it doesn't bother me. It can cause cirrhosis of the liver. But we can keep an eye on things." The doctor I have now is a specialist, but the big thing is to tell those people everything about you. You've got to level with the person you deal with. I never worried about it coming back, with the breast. With the prostate, the risk is a number, and I guess I'm a zero. This hip has been some trouble - I knew as I got older I'd have a few problems, but I didn't know I was going to go to pieces all over (*laugh).* My eyes are pretty well shot, I got one disk fixed up then the one below is gone. So I don't know, I still try to keep a good sense of humor towards life.

I had a friend, a little bit younger than me. He had a prostate cancer operation. He was in good shape, but I don't think he saw a doctor very much in his life. I used to speak to him, and I could feel this whole difference in his whole attitude towards life. And I never knew until the other day - I talked to another friend who said that guy went through a terrible time, a whole lot of pain, that he was really sick but he never did tell me. He'd always say he's good, but I felt that he was a changed man. He's in good shape, now. But I knew there was something wrong.

I don't know how things could be improved. I was treated 100%. Except the radiation doctor, he was pretty withdrawn. As far as the Cancer Clinic goes, I still try to give them a little support for the cause of cancer. I don't know how they make out. We've come a long long way with cancer in the last 25 years. My father died of cancer, lung cancer. They never really did anything for him, because they couldn't - it was too far gone. There was nothing for it 25 years ago. The cobalt they gave him. It was like he was struck with lightning, the marks all over his body. My son is doing well, he's healthy. With his work he has to have a physical every six months.

The only advice I can give is to take care of yourself. Have things looked at, quick. I'm not scared of doctors, I've seen an awful lot of them in the last 5 years. I've got three now: one for cancer, one for the hip and one for regular stuff. Don't be backward about going to get things checked. I think that's the best advice I can give.

Walter's Story

I was invited into a comfortable home in an established area of the City. It was a beautiful summer day, and we sat in a well-appointed front room with the sunlight streaming in. Family photos were everywhere in the room.

It was December 2000 when I first noticed something was wrong. We were in the other City down south. I was shaving and I noticed the left nipple was kind of distorted. I felt it and felt a lump there. So I didn't say anything to my wife until we got home. I went to our doctor who said "oh, this may be something nasty – I'd better send you somewhere else…". So he sent me to the surgeon - that was just before Christmas and he booked me for surgery that day in his office - he was that sure.

But he still sent me for a biopsy, to a lady at the clinic that did breast biopsies. So the surgery was January the 3rd and I went in to the hospital the morning. I was lying there in the bed, and the surgeon comes along and says, "by the way, was that biopsy positive?". I said to him, "this is a hell of a time to be asking that!" (*laughing).* I said, "yes". I had surgery then, and was home by 9 o'clock the next morning.

From the time of the biopsy to the surgery, it was six days - he was so sure. He booked the surgery when I was in his office that day, even before I had the biopsy. He's a great guy, by the way. Apart from that, there was a drain, we drained it every day. The staples came out about a week later. We went to the cancer clinic for an orientation. We talked to the doctor, who was about fourteen years old as I recall, very young (*laughs*). I've been on tamoxifen since, and will be until December then that will be the end.

I didn't really know what to expect, he said it was a radical mastectomy. My sister, I've lost her, she had a mastectomy and her cancer progressed and metastasized later on. She almost went five years; she was 67 when she died. My brother also had cancer, at 56. I didn't have any of those "why me" things, because cancer runs in my family. I guess the scar tissue gets kind of annoying, that's all. The only thing I didn't realize, well, we had a friend at the lake. She asked me if I had any side effects. I said none that I was aware of. She said that her feet were always cold, then I thought, mine were always cold too, but I didn't attribute it to that.

When I went to the cancer clinic, there was nothing on male breast cancer. There was kind of a general orientation. As I recall, it didn't really pertain to me as a person. The oncologist was very good. Another lady radiation doctor said I didn't need any radiation and sent us on our way. I just go back to get my prescription.

I had never heard of men getting breast cancer - it was a total shock to me. Our kids - we're a very close family and our kids were all here. After the surgery, our kids are kind of gutsy. I had the surgery at 4 in the afternoon. After the surgery the kids tracked the doctor down, and he said it was very invasive. I asked our own doctor what I could expect if it progressed. He said that it would go to the other breast, that was the normal

progression. But there's been nothing like that. My worst problem are the cancer spots on my head. Nothing to do with this, that's totally different.

I never ever gave the cancer coming back a thought. I could have, because like with my sister, it was five years plus more then she had to go through the chemo and lost her hair. No, I wasn't concerned. And I'm no spring chicken either, you know. I'm 79 now!

I don't worry about how it looks – I go without a shirt outside, although I shouldn't with my fair skin! It's just the nipple missing, that's all. Everything looks the same, you know. That doesn't bother me.

I don't think any differently about life, I'm the same as ever. Because, maybe if I'd had a recurring problem, we may have reacted different. I honestly say, I never think about it, never. I go to see the surgeon every January. We talk about skiing more than anything else (*laughs*). He's a wonderful guy. I'm the only male patient he's ever had in his 25 years of practise, and he does lots of breast surgery.

For other men, I wonder if men have their doctors check that area - I don't think they do. Maybe men should do that, too. I would also tell another man to think positive. With respect to the cancer clinic, my experience was very positive, so I can't suggest any improvements on what they did for us. The food in the cafeteria was terrible (*laughs).* But every person there was so wonderful. They were considerate and caring. The people at the cancer clinic were very helpful and could answer any questions, so I didn't feel the need to talk to someone who'd had breast cancer. There were support groups available when I went for the consultation, but it wasn't something I considered. I didn't experience any problems - it happened and that's it. If things were different, maybe. But the surgeon took it out and life went on.

Appendix D – Information Sheet and Consent Form

Dear Mr. _____

You are receiving this letter because you are a patient listed in the Alberta Cancer Board Registry. This letter meant to let you know about a research study that you are eligible to participate in if you like, entitled **"The Experience of a Sample of Canadian Men with Breast Cancer".** This study is being conducted by Edith Pituskin RN, MN(c), who is a research nurse at the Cross Cancer Institute and a masters' student in the Faculty of Nursing at the University of Alberta.

This research study has been reviewed and approved by both the Health Research Ethics Board at the University of Alberta and the Research Ethics Committee of the Alberta Cancer Board. These research Boards have asked that men who are eligible for this study be contacted by the Alberta Cancer Registry. In this way you can decide for yourself whether or not to take part in this study.

The Alberta Cancer Registry is a registry of information of all people who have had a cancer diagnosis in Alberta. Cancer registration is the process of collecting information about the rates and kinds of cancer, with the purpose of learning about and controlling the impact of cancer in the community. The activities of the Alberta Cancer Registry are regulated by the Cancer Programs Act.

In this envelope please find the consent form, which will tell you more about the study and what participating would involve. If you are interested in knowing more about this study, please contact **Edith Pituskin** at **(780) 432-8792** or by e-mail at edithp@cancerboard.ab.ca before September 15th, 2005.

Best regards,

Alberta Cancer Registry

The experience of a sample of Canadian men with breast cancer
(a study to learn about the experiences of men who have been diagnosed in the past with breast cancer)

Principal Investigator: Edith Pituskin RN, BScN, MN(c)

Co-Investigators:
Dr. Beverly Williams, Faculty of Nursing, University of Alberta
Dr. Priscilla Koop, Faculty of Nursing, University of Alberta
Dr. Heather-Jane Au, Faculty of Medicine, University of Alberta

INFORMATION SHEET

This form is part of the process of informed consent. It is meant to explain this research study and what will happen if you choose to take part in this study.

If you would like to know more about something mentioned in this form, or have any questions at anytime regarding this research study, please be sure to ask the researcher. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your health care does not depend on whether or not you take part.

This study will take place across the province of Alberta. This study is being performed by a graduate student of the Faculty of Nursing at the University of Alberta in support of a thesis.

Your participation in this study is entirely voluntary. Please take your time to make your decision. You may wish to discuss with your friends and/or family about whether to participate in this study.

BACKGROUND

You are being asked to take part in this study because you are a man who has been diagnosed in the past with breast cancer. Most people know that breast cancer is a common disease in women, however, not many people know than men can get breast cancer, too.

There have been many studies for women with breast cancer examining different kinds of cancer treatment, how women feel about their bodies after treatments, and what women experienced after diagnosis. As there are fewer cases of male breast cancer, doctors and nurses know very little about what men experienced after being diagnosed with breast cancer.

This study is being done because we believe it is important to ask men who have experienced breast cancer what it was like.

PURPOSE

The purpose of this study is to learn about what men experience when diagnosed with breast cancer.

PROCEDURES

If you agree to take part in this study, the researcher will come to your home (or another location that is convenient for both you and the researcher) and ask you what your experience with breast cancer was like. The interviews will each take about 1-2 hours. With your permission, the conversation will be audio-taped, then typewritten later. You may be interviewed 2 or 3 times over a 4 month period by the same researcher. Also, if you think of something afterwards that you would like the researcher to know, you are welcome to telephone and provide this information at a later date.

After the last interview, the researcher will give you a written copy of your story. Since it is your story you may want to make changes before you are given a final copy to keep. A false name will be used to protect your identity.

The researcher will review the stories of the men who participate in this study to see if men had many similar or many different experiences with a breast cancer diagnosis.

POSSIBLE BENEFITS

Participation in this study may or may not be of personal benefit to you. However, you might feel satisfaction in sharing your story with the researcher. You may also enjoy knowing that this study may help other men who are diagnosed with breast cancer.

POSSIBLE RISKS

There are no physical risks that you could experience by having a conversation with the researcher. However, sometimes it can be upsetting to think about or talk about experiences from the past. You are welcome to talk to the researcher about this. If you wish, the researcher will provide you with contact information to the Alberta Cancer Board Psychosocial Services closest to your home. This service is available to you at no cost.

VOLUNTARY PARTICIPATION

Taking part in this study is voluntary; you may withdraw at any time if you wish to do so. During the interview, if you change your mind you may ask the researcher to stop the audiotape recording at any time.

COSTS

There are no costs for you to participate in this study. If it is more convenient for you to meet the researcher in Edmonton, you will receive reimbursement at a standard rate for mileage to and from your house.

CONFIDENTIALITY

Your identifiable health information may need to be inspected or copied from time to time for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organizations may do this inspection:

- Faculty of Nursing at the University of Alberta,
- Health Research Ethics Board of the Capital Health Region,
- Research Ethics Board of the Alberta Cancer Board,
- and the Institute of Gender and Health of the Canadian Institute of Health Research, the granting agency providing funding for this study.

Any disclosure of your identifiable health information will be in accordance with the Alberta Health Information Act. As well, any person from the organizations looking at your records will follow the policies and procedures that control these actions. Any disclosure of your identifiable health information to another individual or organization not listed here will need the approval of a Research Ethics Board.

The researcher who is directly involved in your study may share information about you with other researchers, but you will not be identified in that shared information except by a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with you study and will not be released. Your identifiable health information collected as part of this study will be kept confidential in a secure facility.

CONTACT NAMES AND TELEPHONE NUMBERS

For more information you may contact the Principal Investigator Edith Pituskin RN at (780) 432-8792 or page her through the Cross Cancer Institute Switchboard at (780) 432-8771 (24 hour service) to answer any questions you have about this study.

If you have any concerns about your rights as a study participant, you may contact Dr Kathy Kovacs-Burns, Director of Research, Faculty of Nursing at 780 492-3769 or Kathy.kovacsburns@ualberta.ca.
You may also call the Alberta Cancer Board Patient Representative at (780) 432-8585.

Title of Project: **The Experience of a Sample of Canadian Men with Breast Cancer**

Principal Investigator(s): Edith Pituskin RN, MN(c) Phone Number: (780) 432-8792

Co-Investigator(s):
Dr. Beverly Williams, Faculty of Nursing, University of Alberta (780) 492-8054
Dr. Priscilla Koop, Faculty of Nursing, University of Alberta (780) 492-2692
Dr. Heather-Jane Au, Faculty of Medicine and Dentistry, University of Alberta (780) 432-8762.

Part 2 (to be completed by the research subject):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name _____	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

_____	_____	_____
Printed Name	Signature of Research Subject	Date
_____	_____	_____
Printed Name of Witness	Signature of Witness	Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT